Involving the Public in Research at Bayside Health Peninsula

Facilitator Manual and Learning Resources

SCIENCE FOR ALL

Bayside Health
Peninsula

About

Audience

'Involving the Public in Research at Bayside Health Peninsula' is for clinicians, researchers and health professionals who are interested in learning more about how the public (including patients, carers, consumers and community members) can be involved in their work.

How to use this resource

This document includes a framework of learning areas and learning outcomes designed to support researchers to understand how the public can get involved in health research. This manual has been written so that no formal scientific training is required to use it or deliver training.

Acknowledgements

The first version of this manual was created by Jack Nunn for Peninsula Health in 2016. This updated version was created by Jack Nunn for Science for All and Bayside Health Peninsula in 2026.

Please send any feedback to Jack.Nunn@ScienceForAll.World

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Some of the resources in this manual have been adapted from:

'Building Research Partnerships', created by Macmillan Cancer Support and available under the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International License. More information about that resource can be found here. A STARDIT report about this workshop can be found here: https://stardit.wikimedia.org.au/wiki/0202603250336

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About the session ‘Involving the Public in Research at Bayside Health Peninsula’

About the Session

This interactive workshop will explore how researchers, clinicians, and health professionals can partner with patients, consumers, communities and the wider public in research. Participants will learn:

- What public and consumer involvement in research means and why it matters
- Practical ways to involve people at different stages of the research cycle
- National and international best practices and how they apply locally
- Ways of planning, reporting and evaluating involvement.

Format and timings

- **10:30 - 11:10** Understanding involvement - benefits, methods, and context
- **11:10 - 11:20** Tea Break
- **11:20 - 12:00** Practical steps and action planning

Learning Outcomes

By the end of the session, participants will be able to:

- Explain the importance of consumer involvement in research
- Identify opportunities for consumer engagement in their projects
- Plan next steps for implementing involvement strategies.

Delivery

In order to achieve specific learning outcomes, this session will be delivered using a combination of:

- Pre-prepared learning resources
- Facilitated discussions

Learning resources

All the learning resources created for this session should be shared electronically with all participants after they have attended.

Outline

Session	Summary	Time (min)
Part One Understanding involvement - benefits, methods, and context (**40 minutes** 10:30 - 11:10)		
Introductions and expectations	Sharing experiences and expectations of the session.	5
The what and why of involvement	An exploration of the terms and a discussion about what public involvement in research means and why we do it	10
Exploring examples of involvement at Bayside Health	Sharing different examples of involvement at Bayside Health and exploring best-practice and learning points	10
Planning involvement	An exploration of how to plan involvement	15
Break (11:10 - 11:20)		
Practical steps and action planning (40 minutes 11:20 - 12:00**)**		
Reporting involvement	An exploration of how to plan, report and co-evaluate involvement using STARDIT	15
Developing and sharing plans	Developing and sharing plans for involvement	15
Reflection and next steps	An opportunity for participants to reflect and commit to actions, describe any support needs they feel they have.	5
Closing	Closing remarks and feedback forms	5

Detailed facilitation plan

Session	Summary	Activity instructions	Resources	Time (mins)
Introductions and expectations	● Kim to introduce self and Jack ● Jack to do acknowledgement and housekeeping (fire, toilets, food, TLA) ● Acknowledgement: **Acknowledge all living things which have been here before, are no more, are still here and will be here in the future, with our help.** **The Bunurong/Boon Wurrung people are the traditional people and custodians of the lands from the Werribee River to Wilsons Promontory, and proud members of the Kulin Nation. Bunurong/Boon Wurrung country includes the land around Frankston and the Mornington Peninsula on which Bayside Health Peninsula stands.** **I acknowledge and respect the traditional owners of this land, and their knowledge and care of the land, sea and air. I also acknowledge that sovereignty was never ceded by Aboriginal peoples in Australia, and that this land was not peacefully settled.** ● Briefly summarise the agenda and ask everyone in the group to say their name and what they would like to get out of today (or if not time - do in 2s and 3s). ● Remind participants it is their time, so ask questions or spark discussions ● Housekeeping (including timings) ● Mention knowledge and experience is in the room - today is about sharing ideas as well as exploring if people want to establish a community of practice.		5

Session	Summary	Activity instructions	Resources	
The what and why of involvement	An exploration of the terms and a discussion about what public involvement in research means and why we do it	• Talk about getting our words right - it's important • Ask people what they understand by 'public', 'patient' or 'consumer' involvement and engagement' • State that The National Health and Medical Research Council defines involvement as "research being carried out with or by consumers and community members rather than to, about or for them."[1] • Mention words such as 'engagement', 'involvement' and 'participation' are often used interchangeably, careful articulation is required • Mention it is important to involve 'stakeholders' or 'interest holders' in helping co-define language • Explore the meaning of different terms, ask when each one might be appropriate: 'patient', 'consumer', 'member of the public', 'lay person' • Lead discussion using Diagram of engagement, participation and involvement in research (from Resource 1: Involving the public - what, who and how?) • State you will use the word 'public', to mean all of the terms described by the diagram. • Do research cycle activity - get people standing in the order - ask who has an example of involving people at each stage (use questions from Activity 4)	Resource 1: Involving the public - what, who and how? Resource 16: Research Cycle	10

[1] https://consultations.nhmrc.gov.au/files/consultations/drafts/draftconsstatementconsultationversion140807.pdf

Session	Summary	Activity instructions	Resources	

Exploring examples of involvement at Bayside Health	Sharing different examples of involvement at Bayside Health and exploring best-practice and learning points	• Have 1-2 people share examples of how they have involved people in their work (no more than 3 minutes each)
		• Start to explore questions such as:
		  ○ How did they plan the involvement - who did they involve in planning it?
		  ○ Was there a budget for the involvement? Did they pay people?
		  ○ Who was involved? What tasks did they do?
		  ○ Did they require ethics?
		  ○ What methods did they use to involve people
		  ○ What communication modes?
				10

Planning involvement	An exploration of how to plan involvement	• Talk through the principles of planning involvement, hand out and talk through research cycle and design cycle diagrams
		• Ask people to put their hand up:
		  ○ If they are currently planning or considering involvement - but haven't started yet (group them in 2s or 3s)
		  ○ If they have already started involving people and want support with a specific issue or next step (group them in 2s or 3s)
		  ○ If you have been involved as member of the public
		  ○ If you've just come here to learn and don't have a specific plan or project at the moment (tell them to find a group and join it)
			Resource 2: A Guide To Planning Involvement In Research
			
			Resource 4: Activity instructions
			
			Resource 3: A Template for Planning and Reporting
				15

Session	Summary	Activity instructions	Resources	

		• Work through the following activities:
		The design cycle
		  ○ Activity 1: Stakeholder Mapping - list all the different stakeholder groupings relevant to the research project
		  ○ Activity 2: Which stakeholders are doing which tasks?
		  ○ Activity 3: Mapping interests, preferences and support needs What are the different 'interests' of your stakeholders? Do different stakeholders have different preferences for different ways of working?
		The research cycle
		  ○ Activity 4: The research cycle: For each one of these stages of the research cycle, consider the questions
		• Work through Resource 2: A Guide To Planning Involvement In Research, tell the groups to answer as many questions as possible
		• While they are working they can start to look at Resource 3: A Template for Planning and Reporting Involvement In Research
		• Mention people in groups might be working on more than one - help each other out - ask they questions to each other as prompts
		• Tell them to start working on filling out the template (they can over the break - and we'll come back to it)
			Involvement In Research	

Break (11:10 - 11:20)				

Session	Summary	Activity instructions	Resources	
Reporting involvement	An exploration of how to plan, report and co-evaluate involvement using STARDIT	• Talk about the importance of having a clear plan for involvement • This requires transparent, and ideally, public reporting of involvement • Note that a good plan includes a plan to evaluate the involvement • STARDIT can be used to do this - each one of the fields in the template can be completed online using STARDIT • Activity 5: Planning and reporting: How are you planning your research plan and the involvement plan? At which stages of the research do you intend to report your research plan and involvement plan? • Get groups to complete paper sheet of the template- if people have BYO devices, I can support with them doing that online using a real STARDIT report) • If people in groups are working on different ones, get them to check each others	Resource 3.1: A guide for Planning and Reporting Involvement In Research Resource 3.2: A Template for Planning and Reporting Involvement In Research	15

Developing and sharing plans	Developing and sharing plans for involvement	• Ask people to put their hand up:
		  ○ If they have got stuck or want to discuss something (if just a few - open it up to group - if lots, consider grouping people)
		  ○ If they've made some progress and would be willing to share a summary of their plan
		  ○ Once they have shared it, ask group if they have any thoughts or feedback
				15

Session	Summary	Activity instructions	Resources	Time (min)
Reflection and next steps	An opportunity for participants to reflect and commit to actions, describe any support needs they feel they have.	● Ask people to share anything they have learned or any reflections they have from the session today ● Ask people to share any actions they are going to take ● Has anyone identified any support needs they feel they have? ● Discuss the 'Community of Practice' idea - show of hands if useful?		5
Closing	Closing remarks and feedback forms	● Closing comments from anyone ● Thank you to organisers ● Feedback form		5

Additional activities for participants wanting a focus on involvement in clinical trials

Session	Summary	Activity instructions	Resources	
Reviewing clinical trial documents and research appraisal	Research in the media, research appraisal and reviewing documents	• Ask people to read Resource 17: 'LOMA Phase II clinical trial advert' or consider asking someone to read out the first page. • Give people Resource 18: 'Participant Information Sheet – Phase II clinical trial' and ask them to read it in groups or pairs. • Surprise the group by asking them what they think is good about it. Remind them the role of public involvement is to help make research better. • Ask them if they would take LOMA. Do they have any questions about the research? Have the researchers considered patient experience • Tell them you need multiple perspectives to critically appraise research – give them 'Resource 9: Questions to ask about research'.	Resource 17: 'LOMA Phase II clinical trial advert' Resource 18: 'Participant Information Sheet – Phase II clinical trial'	
Support for involvement in clinical trials	Review and plan for support	• Ask people to read resources 19-21 and reflect on what support they currently have and what support them might need • What support does their organisation or team have or lack? • What about them as an individual? • What would help improve the situation? Encourage action planning	Resources 19-21	

Resources

This section of the manual contains resources which can be used as worksheets or handed out as information to aid discussion.

Each resource is numbered and some are referenced in particular activities.

All the resources are licensed under Creative Commons which is a non-profit organization that enables the sharing and use of creativity and knowledge through free legal tools.

If you are adapting something from this manual or creating something new for it we encourage you to find out more at http://creativecommons.org/.

Please note, if you have any resources you think would be good to include, or any ideas, suggestions or corrections, please email jack.nunn@gmail.com

Presenting, printing and using resources

All the resources in this manual have been designed so that they can be printed easily.

Printing is best done from the PDF version, although it is available in other formats such as Microsoft Word if you would like to edit or adapt materials.

Resource 1: Involving the public - what, who and how?

Getting our words right

It is important that the language used to describe involvement is inclusive and does not unintentionally exclude anyone. Sometimes people may get involved on behalf of themselves, communities defined by shared interests or diseases. Beyond health and medical research, people might get involved in research on behalf of specific species and ecosystems, or whole environments.

As words such as 'engagement', 'involvement' and 'participation' are often used interchangeably, careful articulation is required. Similarly, to be meaningful, words such as 'stakeholder', 'patient', 'public', 'community', 'consumer' and 'payer' also need shared definitions. While terms such as 'people' or 'the public' may exclude fewer people, they also lack specificity. Ensuring words and actions reflect the values of multiple stakeholders can show people that their needs, priorities and interests are inherently valuable and integrated into the research process. In extreme cases, using the wrong words can perpetuate structural violence, discrimination and systemic racism.

Accordingly, it is important to involve stakeholders in helping co-define language, and check that terms being used are acceptable, appropriate and understandable. A short glossary of terms and what is meant by them can be found in the section 'Terminology and definitions'.

Who is involving whom?

Involving the public in research requires an attempt to balance individual autonomy and collective values, in order to ensure the benefits of research and human knowledge are shared equitably.
Variation in people's priorities means that it is important to try to articulate the differences and decision-making processes in a transparent way. Public involvement must be inclusive, and institutions have a moral and legal responsibility to ensure everyone has been supported to get involved in research.

When we say involving the public in research, we include people from any communities of shared interest, people who use health or care services, (including patients, carers, service users), consumers or users of specific technology or services, people with specific personal experiences, people from specific cultural or linguistic communities, people from communities defined by recent shared ancestry, people affected by specific environmental phenomena, and the general public.

The interrelationship between the terms 'engagement', 'participation' and 'involvement' in the context of research is illustrated in the 'Diagram of engagement, participation and involvement in research', and a full articulation of the word 'stakeholder' is provided in the section 'Stakeholder Groupings'.

Stakeholder Groupings

The table below articulates the different stakeholder groupings implied by the word 'stakeholders', in the context of research, policy and services. It is important to note the word 'groupings' is used, to recognise that the act of grouping people can either be done collaboratively (with people) or done to people, without their involvement or consent.

Unintended harms can be caused by grouping people and creating descriptions about communities that are not in alignment with the way the people from those communities view themselves. Grouping people in ways which do not align with their own values or beliefs can perpetuate structural violence towards people, especially when research is done 'on' people, rather than with them. For example, some people who identify as members of the 'Deaf community' believe that being deaf is a form of human diversity, and need not be understood as a disease or disability.

When working with Indigenous peoples in countries such as Australia, it is of particular importance to understand and acknowledge both the history and continued evidence of systemic racism and structural violence towards Aboriginal peoples. The Australian Department of Health document *'Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders'* provides a set of principles to ensure research is safe, respectful, responsible, high quality and of benefit to Aboriginal and Torres Strait Islander people and communities. Ethical research with Aboriginal and Torres Strait Islander Peoples and communities should:

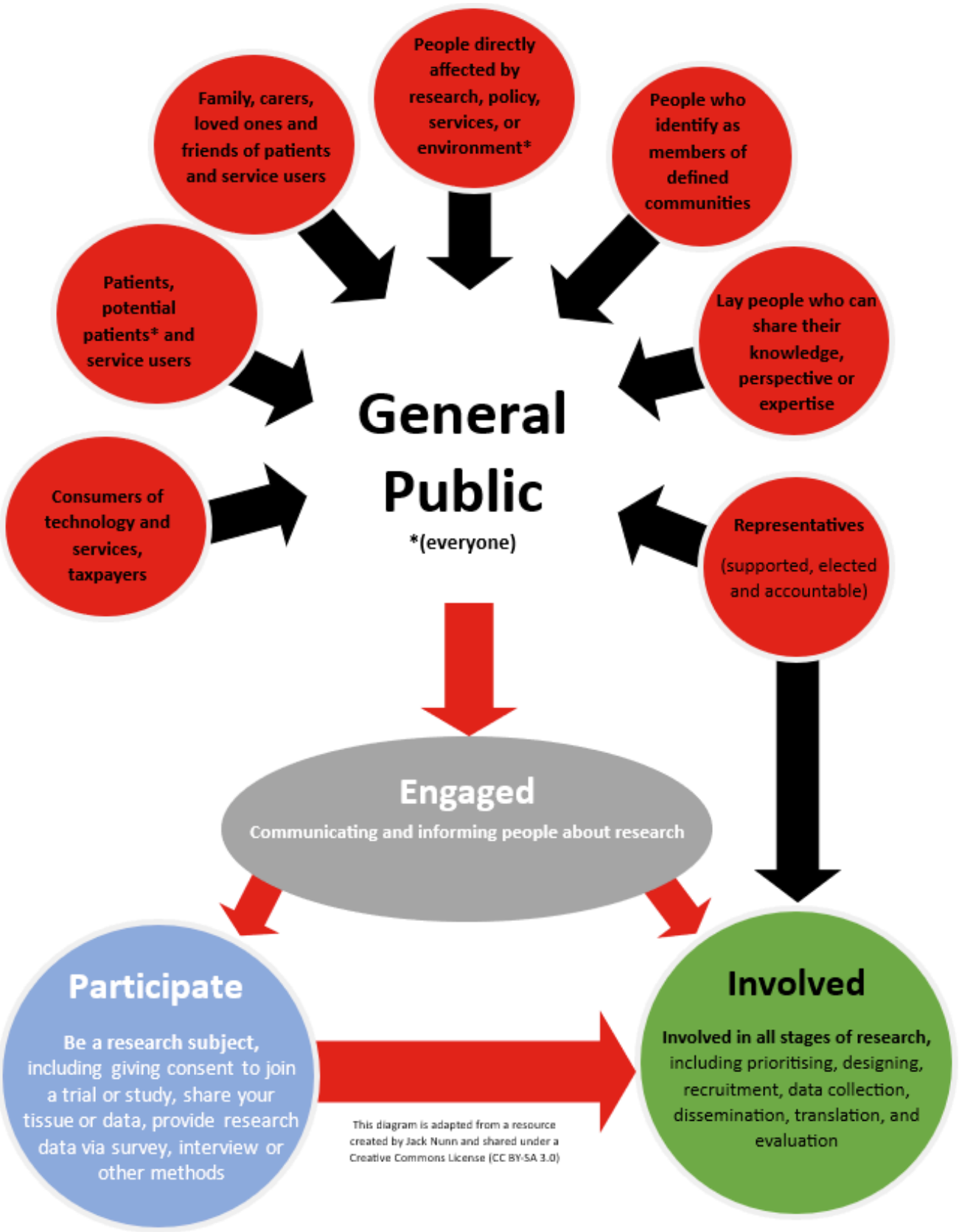
- Improve the way all researchers work with Aboriginal and Torres Strait Islander people and their communities.
- Develop and/or strengthen the research capabilities of Aboriginal and Torres Strait Islander people and their communities.
- Enhance the rights of Aboriginal and Torres Strait Islander Peoples as researchers, research partners, collaborators, and participants in research.

Ensuring words and actions reflect the values of multiple stakeholders can show people that their needs, priorities and interests are inherently valuable and integrated into the research process in a way which extends beyond simply improving recruitment for a study. The table below summarises some of the more common stakeholder groupings, and articulates further what can be meant by the term 'the general public'.

	Stakeholders					
Organisations	**Industry**		**Research and educational Institutes**		**Government**	*Public*
	For-profit	Not-for-profit (charity)	University	Independent	Departments and Committees (local, State and Federal)	(See diagram on next page)
	Investors, share-holders	Donors	Researchers and educators		Elected representatives, civil servants, and Government employees	
People	Employees, casual workers, consultants, and paid advisors					
	Owners of intellectual property, physical property, and goods					

Please note: in the table above, 'government' has been included as a stakeholder, although technically in a representative democratic system (such as Australia), the general public is the stakeholder which has devolved governance and decision-making to elected representatives and 'public servants' who, in theory, act in the public interest.

Diagram of engagement, participation, and involvement in research


People directly affected by research, policy, services, or environment*
Family, carers, loved ones and friends of patients and service users
People who identify as members of defined communities
Patients, potential patients* and service users
Lay people who can share their knowledge, perspective or expertise
General Public
*(everyone)
Consumers of technology and services, taxpayers
Representatives
(supported, elected and accountable)
Engaged
Communicating and informing people about research
Participate
Be a research subject, including giving consent to join a trial or study, share your tissue or data, provide research data via survey, interview or other methods
Involved
Involved in all stages of research, including prioritising, designing, recruitment, data collection, dissemination, translation, and evaluation
This diagram is adapted from a resource created by Jack Nunn and shared under a Creative Commons License (CC BY-SA 3.0)

Terminology and definitions

Words can mean different things to different people. The important thing when using a word or phrase, is to define what **you** mean by it, and be consistent. Some common words and the related concepts are defined in this resource. Some words and concepts are linked to WikiData in order to standardise terminology where possible. Created in October 2012, "Wikidata is a large-scale, human-readable, machine-readable, multilingual, multidisciplinary, centralized, editable, structured, and linked knowledge-base". Terminology in these definitions has been informed by multiple sources, including the International Association for Public Participation (IAP2) 'Public Participation Spectrum'.

Table 1: Defining words and concepts

Word (Wikidata entry)	Definition
Barriers (Q109580927)	Barriers refers to things that might prevent something from happening.
Community (Q177634)	A group of people sharing a common interest or values (e.g. cultural, social, political, health, economic interests) but not necessarily a particular geographic association. Different types of communities are likely to have different perspectives and approaches to their involvement in research. (NHMRC definition)
Consumer	Consumer –The NHMRC states consumers are 'patients and potential patients, carers, and people who use health care services' (in the Statement On Consumer And Community Involvement In Health And Medical Research)
Enablers (Q109580938)	Enablers refers to things that help enable something to happen. For example, paying people's travel expenses might enable them to get involved in research.
Engagement (Q120727104)	When information and knowledge about research is shared with the public so that they are better informed on why, how, where and by whom research is conducted. When people are engaged they are being 'told' about something, rather than 'doing it'. **Note**: As 'engagement' and 'involvement' are used interchangeably by some, the definition of engagement above in this Strategy is used to distinguish it from the active involvement of stakeholders. (Adapted from Australian Genomics Guidelines for Community Involvement in Genomic Research)
Lay person (Q120943280)	The word 'lay' comes from the Greek word 'laikos' which means "of the people". A layperson has come to mean someone who is a non-professional in a given area of knowledge. In the context of research, it describes someone who is not qualified in a certain area, but recognises the value of the 'non-expert' perspective they have. The term 'lay person' therefore refer to any member of the public who is a non-expert in a specific area of knowledge (hence a 'lay' summary being a summary written for anyone to understand). Examples in context: "Lay involvement in the analysis of qualitative data in health services research" https://doi.org/10.1186/s40900-016-0041-z
Open Science (Q309823)	The UNESCO Recommendation on Open Science defines open science as "an inclusive construct that combines various movements and practices aiming to make multilingual scientific knowledge openly available, accessible and reusable for everyone, to increase scientific collaborations and sharing of information for the benefits of science and society, and to open the processes of scientific knowledge creation, evaluation and communication to societal actors beyond the traditional scientific community. It comprises all scientific disciplines and aspects of scholarly practices, including basic and applied sciences, natural and social sciences and the humanities, and it builds on the following key pillars: open scientific knowledge, open science infrastructures, science communication, open engagement of societal actors and open dialogue with other knowledge systems" • Example in context: "as a global public good, open science should belong to humanity in common and benefit humanity as a whole"
Participation in research (Q120727340)	Participation in research is where a person voluntarily partakes in human research after giving informed consent to be the subject of the research as a passive participant.

Word (Wikidata entry)	Definition
	Note: As 'participation' and 'involvement' are used interchangeably by some, 'participation' has been defined in this Strategy as above to avoid confusion between 'involving the public in research', and the ethically distinct act of participation in research. (Adapted from Australian Genomics Guidelines for Community Involvement in Genomic Research)
Participatory action research (Q7140444)	Participatory action research is an umbrella term which describes a number of related approaches, including forms of action research which embrace a participatory philosophy and include 'co-design' and 'co-production' of research.[1] It is a process whereby researchers, the public and other relevant stakeholders "work together, sharing power and responsibility from the start to the end of the project", including knowledge generation and translation.[2]
Public interest (Q29627)	A sense of "common well-being" or "general welfare" of the public, society or humanity. The term is used specifically in the context of human society, rather than environmental systems.
Public involvement (Q124607879)	When anyone from the public can be actively, transparently and meaningfully involved in a process, including influencing the development, implementation, and evaluation of policies, initiatives, research and services that impact them.
Public involvement in research (Q109581008)	Public involvement in research refers to research being carried out 'with' or 'by' members of the public, rather than 'to', 'about' or 'for' them. This can include working to prioritise research topics, helping design research, helping manage it, and helping evaluate it. (Adapted from INVOLVE 'What is public involvement in research?')
Representative (Q11997597)	A person who speaks for or acts on behalf of another person, or a defined group or community. This includes taking part in the decision-making process on behalf of others.
Stakeholder (Q109581040)	The term 'stakeholder' is used here to mean anyone who has a 'stake' in research, services, policy, products or other initiatives. In particular, the term includes those with important knowledge, experiences, expertise or views that should be taken into account. It can include: researchers, research funders, policy makers, people affected by the research, people with specific health conditions, people with specific genomics variations, patients, and the general public (including 'tax-payers' for publicly funded research).
The public, 'general public' or 'people' (Q2388316)	The term 'people' and 'the public' is used to refer specifically to patients, potential patients, carers, payers, consumers of health technology and the general public, excluding professional researchers, research funders, policy makers and anyone else with a professional connection to research. The public is everyone in society, and the term may extend beyond national borders to encompass all humanity. The NHMRC states "Collectively, 'consumers' and 'community members' may be referred to as 'the public'" (in the Statement On Consumer And Community Involvement In Health And Medical Research)

Resource 2: A Guide To Planning Involvement In Research

Planning how different stakeholders will be involved in research should be an intrinsic part of the research plan, with a distinct method and appropriate resourcing (budget and staff time).

Ideally, this 'Involvement Plan' should itself be co-designed with appropriate stakeholders to ensure the plan is appropriate, realistic and not exploitative. Planning for involvement should start as early as possible, with involvement activities ideally shaping the research project or question, sometime well before a project is itself funded.
The following guide divides planning for involvement into three distinct stages, which will ideally take place before the research begins. This guide has been written as a series of reflective questions to help you consider different aspects of the Involvement Plan.

Stage 1: Reflection, mapping and planning

- **What are you doing and why?**
  - Do you or your colleagues have a clear idea of who is doing what, or you plan to do?
  - Why are you doing it? What are **your** motivations? Are everyone else's motivations clear to everyone else? Do you, your colleagues or organisation have stated values?
  - Are you supported sufficiently? Do you have enough time to do this?
- **Why do you want other people involved?**
  - What is the motivation? Is it to improve the quality of research, the relevance or the dissemination and translation of the research? Is it to ultimately improve lives?
- **Who will be involved and how?**
  - **Who is doing which tasks?** Are there different stakeholder 'groupings'? Groupings can include: Professional researchers, experts, people directly affected by the research, people with specific experiences which can inform the research, interested members of the general public
- **What might enable or inhibit their involvement?** What support might they need to be involved?
  - Who is being paid, who isn't?
  - Have you budgeted for staff or researcher time, including for the Involvement Plan
  - Will you offer training?
  - Will you offer other appropriate support (paying for travel, IT equipment, emotional support)
  - **What methods will you use?** Co-*what*?

Consultation?	**Co**-creation?	**Co**-investigator?
	Time X Resourcing	

Conduct surveys	**Co**mmittee	**Co**lleague or Co-author

- **What communication modes will you use?**
    - In person meetings? Video calls? Emails and shared documents? Online text-based discussions? Telephone interviews? Online surveys?
- **How, where and when will you recruit stakeholders to be involved?**
- **Do you need ethics approval for your involvement plan?**

Stage 2: Refining the plan

Once you have a draft 'Involvement Plan', recruit a number of stakeholders to review and refine it. For example:

Method	Interim Steering Committee
Tasks	1: Review and comment on involvement plan 2: Collaboratively map stakeholders 3: Collect information about different stakeholders' preference for involvement (some stakeholders might prefer different methods or communication modes) 4: Report different 'interests' of stakeholders (personal, professional or financial interests) and if there are any 'conflicting' or 'competing' interests
Modes	Video calls, commenting on shared documents
Recruitment	Public link to expression of interest or application *or* invite only
Enablers	People will be paid $100 an hour and offered training and appropriate support
Resourcing	Appropriate resourcing (including budget and staff time) has been allocated
Ethics	Ethics approval has been granted for this Involvement Plan

Stage 3: Begin the Involvement Plan

On the next page, 'Figure 1: Public Involvement in Research' summarises the research cycle, and gives examples of tasks that the public (including patients, carers, communities and consumers) can be involved in.

If your project is still at the conceptual or design stage, 'Figure 2: Public involvement and Research Design' provides a simplified 'design cycle' (which is itself part of the research cycle), and gives examples of tasks that the public can be involved in.

While it is best practice to plan how you will involve the public in each stage of the research from the start, you can still start planning at any stage of the research, even if it's just for the final stages.

How do we involve the public in research?

We can involve the public in research by actively supporting people to be involved in:

- **shaping our priorities and what we do** - ensuring our research is relevant and acceptable
- **defining what is likely to be acceptable to the public** – particularly in ethically sensitive research
- **improving the research process** – making it easier for the public and prospective participants to understand the research and its potential risks and benefits
- **improving the experience of participants in research** – including checking the methods are appropriate and ethically acceptable for human or non-human research participants
- **improving the interpretation of data and evaluation of the research** – including interpreting data and evaluating research methods
- **improving the communication** – including sharing data, findings and involving people in implementing learning from research
- **improving the impact assessment of the research** – including unexpected or unintended impacts

This section was p*artially adapted from*
https://www.hra.nhs.uk/planning-and-improving-research/best-practice/public-involvement

Figure 1: Public Involvement in Research

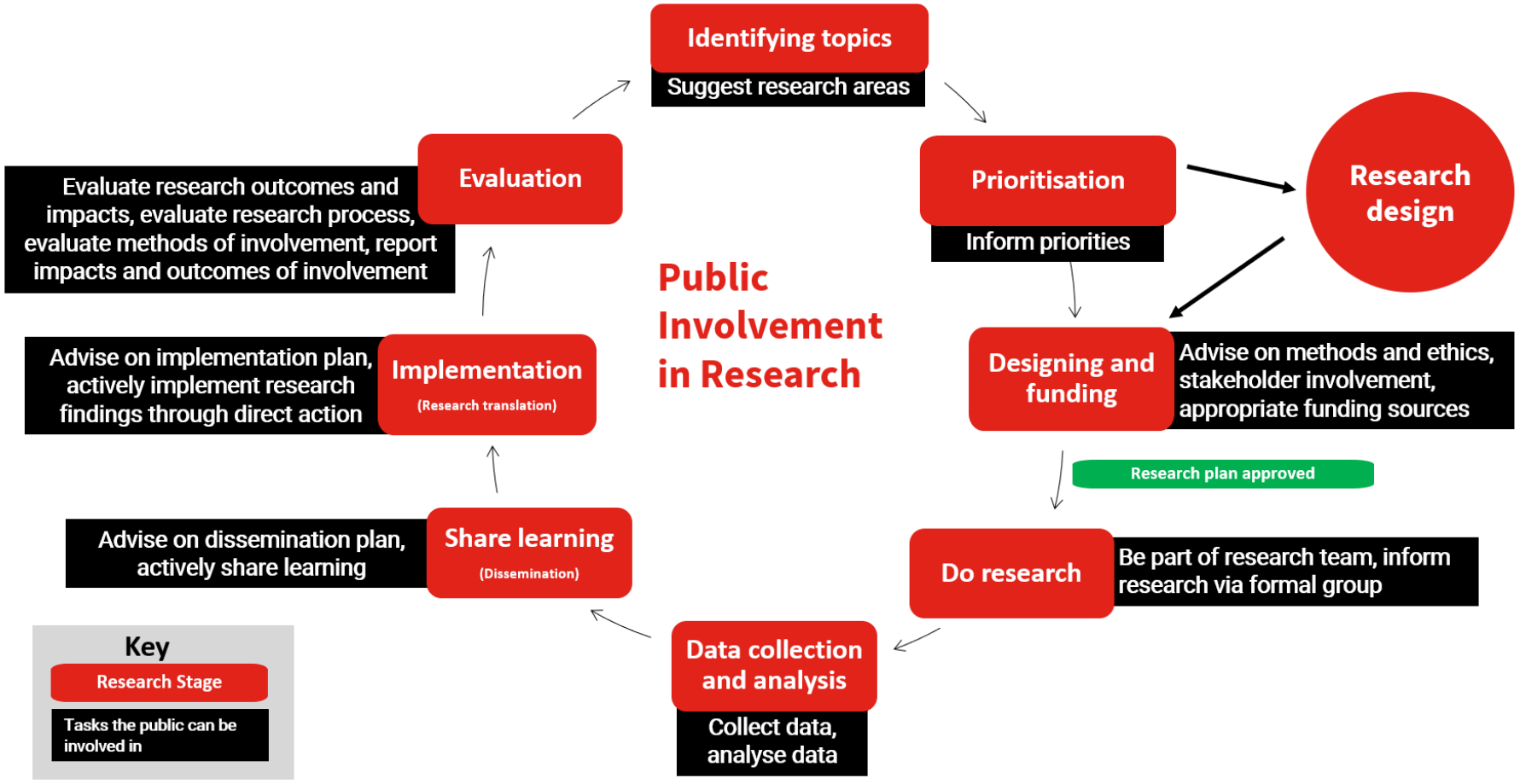
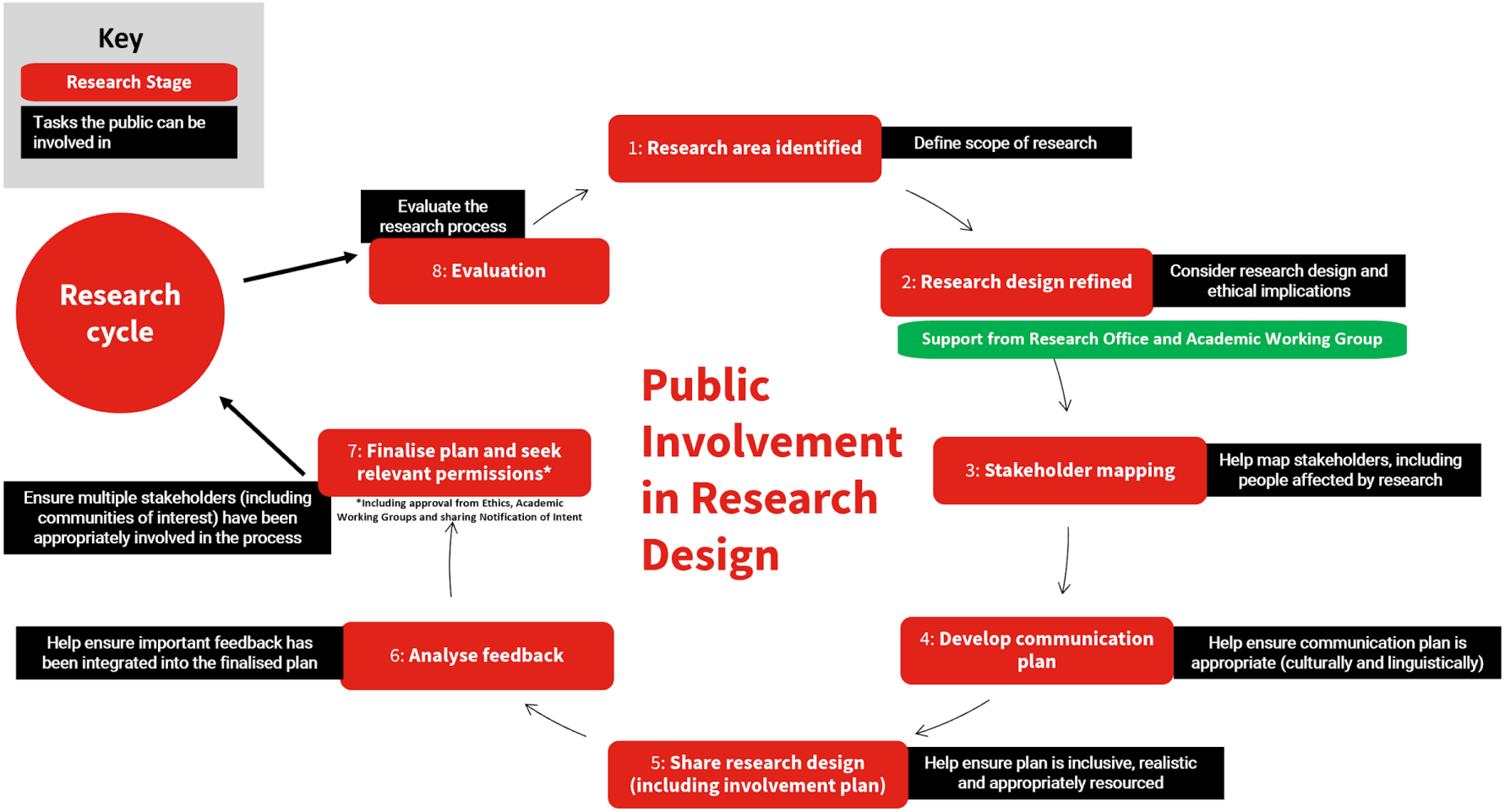

Identifying topics
Suggest research areas
Prioritisation
Inform priorities
Research design
Designing and funding
Advise on methods and ethics, stakeholder involvement, appropriate funding sources
Research plan approved
Do research
Be part of research team, inform research via formal group
Data collection and analysis
Collect data, analyse data
Share learning
(Dissemination)
Advise on dissemination plan, actively share learning
Implementation
(Research translation)
Advise on implementation plan, actively implement research findings through direct action
Evaluation
Evaluate research outcomes and impacts, evaluate research process, evaluate methods of involvement, report impacts and outcomes of involvement
Public Involvement in Research
Key
Research Stage
Tasks the public can be involved in

Figure 2: Public involvement and Research Design


Key
Research Stage
Tasks the public can be involved in
Research cycle
Public Involvement in Research Design
1: Research area identified
Define scope of research
2: Research design refined
Consider research design and ethical implications
Support from Research Office and Academic Working Group
3: Stakeholder mapping
Help map stakeholders, including people affected by research
4: Develop communication plan
Help ensure communication plan is appropriate (culturally and linguistically)
5: Share research design (including involvement plan)
Help ensure plan is inclusive, realistic and appropriately resourced
6: Analyse feedback
Help ensure important feedback has been integrated into the finalised plan
7: Finalise plan and seek relevant permissions*
*Including approval from Ethics, Academic Working Groups and sharing Notification of Intent
Ensure multiple stakeholders (including communities of interest) have been appropriately involved in the process
8: Evaluation
Evaluate the research process

Reporting involvement

At which stages of the research do you intend to report your research plan and involvement plan?

For example, you could publish your research plan and involvement plan by publishing a peer-reviewed protocol. You can also report it retrospectively in a peer-reviewed publication.

A novel way of planning and reporting is using 'Standardised Data on Initiatives (STARDIT)' to report at each stage, with the report marked as prospective, ongoing or completed. You can update it at each stage, make changes and involve multiple stakeholders in creating, editing or verifying it. Learn more here:

ScienceForAll.World/STARDIT

The 'Resource 3: A Template for Planning and Reporting Involvement In Research' been written to align with the 'Standardised Data on Initiatives' (STARDIT) reporting tool.

STARDIT has been recommend for us by Australian Genomics. For more information, visit: ScienceForAll.World/STARDIT

Other tools to report involvement include including:

- Guidance for Reporting Involvement of Patients and the Public 2 (GRIPP2) reporting checklists
- Public Involvement Impact Assessment Framework (PiiAF)

By reporting your planned involvement **before you start**:

- You can demonstrate to stakeholders how you plan to involve people, and let them assess if they think this is realistic, appropriate and acceptable
- Allow potential funders to assess the level of stakeholder involvement, and if this is appropriate

By reporting your involvement once it is ongoing and completed:

- You can help people critically appraising your research in deciding how stakeholder involvement influenced the research
- Help others learn from your involvement, especially by sharing barriers, enablers, impacts and outcome

Resource 3.1: A guide for Planning and Reporting Involvement In Research

This is a guide to completing the template (Resource 3.2), where you can outline the plan for the research, including how different people will be involved in different tasks. All categories are aligned with STARDIT data fields, which can be used to report the initiative at all stages. Please note as this is a planning template the future tense is used, but present and past events can also be reported. Please note the data fields here are the 'Minimum Contribution' fields, further are available when completing the report. Visit: ScienceForAll.World/STARDIT

Section	Data fields	Guidance for completing the data field		
Initiative context	Initiative name	What is the name or title of the project, initiative or research?		
	Initiative type	Is it research, arts, education, policy, information, media, product, health and social care services?		
	Description	Summarise the project in 1500 characters in plain language as if writing for a 'non-expert' audience		
	Aims	What are the goals, objectives or purpose of this initiative?		
	State	Is this report about an initiative which is **prospective**, **ongoing** , or **completed**?		
	Location	What is the geographical scope of this initiative? For example, 'Australia' or 'global'		
Report Authors	Report authors	Who wrote this report? Who checked the report? Who contributed in other ways (such as editing information)		
	Contact	Is a report author a contact for the initiative? Is the report author affiliated or unaffiliated with the initiative?		
Contributor information	Contributors	**Type**: Who will contribute to this initiative? This can be an '**individual'**, '**grouping of individuals'** or an '**organisation'**. Example: 'Grouping of individuals'	**Name**: What is the name of the individual, grouping of individuals (number?) or organisation? Example: Project Steering Committee (10)	**Tasks** (current status): What are the tasks of **individual**, **grouping of individuals** or **organisation** (or planned or completed)? Example: project design (completed), management (ongoing) and data analysis (planned)
	Method	How will this contributor involved? Example: formal committee with Terms of Reference		
	Communication	What modes of communication will be used? Example: In person meetings, video calls, shared online documents?		
	Recruitment	How will people be recruited or invited to contribute to the initiative? Example: Public web-link, email invite		
	Compensation	How will this contributor be compensated or remunerated? Example: payment, honorarium, gift, no compensation		
	Cost	What was the estimated financial cost for involving each individual, grouping or organisation who contributed?		
Other inputs	Financial	What are the estimated financial inputs for this project (how much will it cost?), describe who is paying and provide and public links to information		
	Time and 'other'	How much time is being given to this project? For example, 'in-kind', pro bono or voluntary hours? Any other resources?		
Ethics	Ethics status	Does this initiative need ethics approval? Example: 'Not applicable', 'ethics approval being sought' or 'approved'		
	Ethics details	Which organisation provided approval? What was the date? What is the ID? Can you provide a link to it?		

Section	Data fields	Guidance for completing the data field
Assessing Inclusivity	Enablers of contribution or involvement	What are the anticipated factors which might enable people to contribute or be involved in the initiative? Example: paying people for time or travel, using accessible technology to conduct online meetings
	Barriers of contribution or involvement	What are the anticipated factors which might inhibit or prevent people from contributing or be involved in the initiative? Example: Not paying people for time, not offering any translation services, only meeting in-person (not online)
Contribution Information	Contributor Interests	What are the financial, personal, professional or other interests of the contributor (including conflicting or competing interests)? Example: All members of the Project Steering Committee are people living with or caring for people with dementia
	Contributor Impacts	What **changes to the initiative** do you anticipate or report as a result of this contribution? Example: The Project Steering Committee changed the scope of the research project from just researching the experiences of people with dementia, to including parents and carers of people with dementia
	Impact stage	What date or stage of the initiative did this impact occur? Example: Planning stage, implementation, data analysis
Outputs and impacts	Output type	What is the type of output? Example: Publication, report or document ? Dataset? Event? Change? Learning item? Knowledge translation? Other type?
	Output description	What came from the work done (e.g. changes made, events held, data and documents produced, things learnt or other results)? When describing these, attempt to label which groupings were affected and how. These can include impacts on people, organisations, processes or other kinds of impacts.
	Learning	What new knowledge was generated? If appropriate include effect size, relevant statistics and level of evidence
	Knowledge translation	How what was learnt **has** or **will** be used
	Impact of output	Impact or effect of the output

This resource is adapted from 'A Guide to Planning Involvement In Research', produced by Jack Nunn for the charity Science for All, https://archive.org/details/a-guide-to-planning-involvement-in-research-v-1-2024.01.15

Resource 3.2: A Template for Planning and Reporting Involvement In Research

By completing this template, you will have outlined the plan for the research, including how different people will be involved in different tasks. All categories are aligned with STARDIT data fields, which can be used to report the initiative at all stages. Please note as this is a planning template the future tense is used, but present and past events can also be reported. Please note the data fields here are the 'Minimum Contribution' fields, further are available when completing the report. Visit: ScienceForAll.World/STARDIT

Section	Data fields	Data field		
Initiative context	Initiative name			
	Initiative type			
	Description			
	Aims			
	State	(Prospective, ongoing, completed)		
	Location			
Report Authors	Report authors	(You)		
	Contact			
Contributor information	Contributors	**Type**: Who will contribute to this initiative?	**Name**: *Example: Project Steering Committee (10)*	**Tasks** Example: *project design*
	Method			
	Communication			
	Recruitment			
	Compensation			
	Cost			
Other inputs	Financial			
	Time and 'other'			
Ethics	Ethics status			
	Ethics details			

Section	Data fields	Data field
Assessing Inclusivity	Enablers of contribution or involvement	
	Barriers of contribution or involvement	
Contribution Information	Contributor Interests	
	Contributor Impacts	
	Impact stage	
Outputs and impacts	Output type	
	Output description	
	Learning	
	Knowledge translation	
	Impact of output	

This resource is adapted from 'A Guide to Planning Involvement In Research', produced by Jack Nunn for the charity Science for All, https://archive.org/details/a-guide-to-planning-involvement-in-research-v-1-2024.01.

Resource 4: Activity instructions

These activities can be done as an individual or as a group. They are designed to encourage reflection and planning in relation to involving different stakeholders in research.

Activity 1: Stakeholder Mapping

Instructions: list all the different stakeholder groupings relevant to the research project - groupings include:

- Researchers, investigators, partners, stakeholders (including 'patients', 'consumers' and the 'public'), research participants, industry, government, academia, community (defined by geography or shared interest?)

Note that people should pay particular attention to thinking about who the research is intended to benefit

Activity 2: Which stakeholders are doing which tasks?

If you are still designing your research – consider which stakeholders would you involve in the following tasks?

- Identifying ideas (research questions, methods, interventions)
- Refining idea, research question, method and intervention (e.g. who could give feedback?)
- **Stakeholder mapping** (**you've** done **your** initial mapping, but which stakeholders might be good to involve in further mapping – e.g. community members might know of relevant local organisations)
- **Develop a communication plan** (who will you tell about this initiative, what modes of communication, who will help you tailor it to various audiences/stakeholder groupings?)
- Share information about this idea or initiative, including the Involvement Plan (who will be involved, which tasks, what methods, what communications modes?)
- Analyse feedback on the idea or initiative (including feedback on the involvement plan)
- Finalise the plan and seek relevant permissions (ethics, consent, land owners, traditional custodians)

Activity 3: Mapping interests, preferences and support needs

What are the different 'interests' of your stakeholders? Do different stakeholders have different preferences for different ways of working? (online, in person, synchronous/asynchronous)

- Mapping interests
  - Which of these stakeholders or stakeholder groupings has an 'interest' and what kind of interest? (personal, professional, financial, other?) – could it be perceived as a conflicting or competing interest?
- Mapping preferences
  - Might different stakeholders have different preferences for ways of working (methods of being involved, communication modes?)
- Mapping support needs
  - What different support needs might different stakeholders have?
    - **Financial**: can everyone afford to volunteer? Who will you pay for their time or travel
    - **Practical**: how can you use accessible technology to involve people?
    - **Learning**: what learning needs might different stakeholders have?
    - **Emotional**: Do you need to consider supporting people's emotional needs?

Activity 4: The research cycle

If you've worked through the design cycle, you can work through the research cycle.
For each one of these stages of the research cycle, consider the following questions:

- **Sharing idea** – who is involved in giving feedback, how? Who is paid, who isn't? Who has an 'interest', and what kind of 'interest'?
- **Prioritisation** – is this a priority? For who? Why? What else might be a priority? Who have you involved in identifying topics and prioritising them (See: James Lind Alliance Priority Setting Partnerships)
- **Designing and resourcing** – where is the most appropriate place to get funding? If you have been funded, do you need additional funding or resourcing? Have you involved stakeholders in identifying other funding sources, and exploring other kinds of in-kind support or resourcing?
- **Do initiative** – who is doing which tasks at which stages? (this is a big one!)
- **Data collection and analysis** – who is collecting it, analysing it, checking it. Who is involved in checking your data storage plan?
- **Sharing learning** – who is a co-author? (who is paid?), where are you sharing results and learning, what data are you sharing, what data aren't you sharing? Who was involved in deciding this?

Activity 5: Planning and reporting

How are you planning your research plan and the involvement plan? At which stages of the research do you intend to report your research plan and involvement plan?
For example, you could publish your research plan and involvement plan by publishing a peer-reviewed protocol (which is always a good thing to do – but sometimes by the time it's published, the project is halfway completed!)

A novel way of planning and reporting is using 'Standardised Data on Initiatives (STARDIT)' to report at each stage, with the report marked as prospective, ongoing or completed. You can update it at each stage, make changes and involve multiple stakeholders in creating, editing or verifying it. Learn more here: ScienceForAll.World/STARDIT
You can complete a plan using the shared working document (link shared in chat), or by working through Resource 3: A Template for Planning and Reporting Involvement In Research.

Resource 5: Key information from MRFF about involvement

This resource is adapted from 'Principles for Consumer Involvement in Research - Advice from the Medical Research Future Fund Consumer Reference Panel – March 2023' *https://www.health.gov.au/sites/default/files/2023-03/principles-for-consumer-involvement-in-research-funded-by-the-medical-research-future-fund.pdf*
Document adapted under Creative Commons Attribution 3.0 licence

Summary of consumer involvement in MRFF

Consumers are the ultimate funders, users and beneficiaries of health and medical research and innovation. They have valuable contributions to make to research and a right to be involved. Many consumers want to be involved in health and medical research and to be involved beyond a role of 'participant' or 'subject'.

The object of the Medical Research Future Fund (MRFF) is to improve the health and wellbeing of Australians. Our collective ability to achieve this is enhanced by effectively involving consumers in the prioritisation, design, conduct, translation and evaluation of research funded by the MRFF as well as in the selection of funded research projects.

Consumers bring a broad range of valuable perspectives and experiences, such as diversity in culture, linguistics, gender and ability, that can improve the quality, relevance and impact of research.

There is evidence that involving consumers can build trust between researchers and consumers[2], increase recruitment of participants[3] and improve the quality, outcomes, relevance and impact of the research.[2,4]

Strengthening consumer involvement in MRFF-funded research is important to align Australia's health and medical research conduct with international best practice, and to further build the quality and international competitiveness of Australian research.

Strong and effective consumer involvement requires strong consumer engagement skills and approaches by research teams, adapted to each unique project. It also requires engagement from, encouragement by, and facilitation through, all areas of the health and medical research sector – including but not limited to research funders, research organisations, researchers, professional bodies, industry, consumer organisations, consumers, and community members.

[2] A Anderst et al, 'Engaging consumers in health research: a narrative review', *Australian Health Review*, 2020, 44(5): 806-813, doi.org/10.1071/AH19202.
[3] J Crocker et al, 'Impact of patient and public involvement on enrolment and retention in clinical trials: systematic review and meta-analysis', *BMJ*, 2018, Nov 28;363:k4738, doi: 10.1136/bmj.k4738.
[4] J Brett et al, 'Mapping the impact of patient and public involvement on health and social care research: a systematic review', *Health Expectations*, 2012, 17: 637–650, doi.org/10.1111/j.1369-7625.2012.00795.x.

Principles for Consumer Involvement in Research Funded by the Medical Research Future Fund

Advice from the Medical Research Future Fund Consumer Reference Panel

A consumer is a person with lived experience as a patient, client, potential patient, user of health services, and/or providing support as a carer, family or community member.

It is the view of the Consumer Reference Panel that to achieve the best quality, outcomes and value for money in MRFF funded research, consumers should be involved:

- In every type of research, including basic science, public health, preventive health, translation and clinical research.
- At all stages of research, from defining the need/priority of a research question, refining the research question and research design through to conduct of the research and sharing and translation of results.
- In partnership with researchers, with consumers respected and recognised for the valuable and complementary knowledge, expertise and perspectives they bring to the research.
- Effectively, with sufficient time, resources and depth of relationships to enable consumers to understand and actively engage with and contribute to the research.
- Sensitively and safely, through research teams with strong and broad capacity and capabilities in consumer involvement, appropriate training and a supportive environment for consumers, and clearly defined and agreed roles.
- With broad diversity and equity, with the goal of increasing involvement of priority populations through culturally safe and appropriate engagement.

The form and level of consumer involvement should be appropriate to the specific project and to that cohort of consumers.

The Consumer Reference Panel has also put together guidance for researchers on what these Principles could look like in practice. This guidance is provided at **Attachment 1 - Implementation Guidance**.

Attachment 1 - Implementation Guidance

The Consumer Reference Panel has provided the following advice to support researchers, research organisations, other relevant stakeholders and consumers to achieve best practice consumer involvement as a strategy for supporting the best possible outcomes from MRFF funded research.

While expected across all research projects, it is noted that addressing every dot point below in every research project is aspirational. Also, the form and level of consumer involvement should be appropriate to the specific project and to that cohort of consumers.

To achieve best practice consumer involvement, MRFF grant applicants and prospective grant applicants would:

- Build ongoing, productive, two-way relationships with consumers, consumer representatives, consumer advocates, and consumer organisations, as appropriate to their area of research.
- Engage with diverse communities as relevant to their area of research, including Aboriginal and/or Torres Strait Islander people, culturally and linguistically diverse people, older people experiencing diseases of ageing, people with rare or currently untreatable diseases/conditions, people in remote/rural communities, people with a disability, LGBTIQ+ people, and youth.
- Work with consumers to understand consumer priorities.
- Involve consumers in defining the need, priority, and framing of the research question.
- Regularly consult with consumers to understand how consumers want to be involved in the research project through design, conduct, dissemination, and translation.
- Work with consumers to co-design the research project.

To achieve best practice consumer involvement, within an MRFF grant application, applicants would:

- Describe how their project aligns with consumer needs, values, and priorities, and benefits consumers, and how this alignment has been achieved.
- Describe how, when, and in what roles consumers have been and will be involved in the ongoing conduct and dissemination of the research (e.g., governance, oversight, recruitment, consent, ethics, communications, publications, translation, as a chief/associate investigator).
- Describe how consumer involvement is embedded across various project governance levels, and ensures sufficient peer support for consumers (e.g., more than one consumer on each committee).
- Describe how consumer involvement is inclusive and diverse, as appropriate to the project (e.g., age, gender, geographic association, socio-economic status, cultural and linguistic diversity). If any groups are excluded from the research population, explain why.
- Describe how effective support, training, and information will be provided to consumers to allow them to contribute to their full potential.
- Describe how an environment where consumer involvement is safe, sensitive, and respectful will be provided.
- Outline how their research team has the appropriate skills, capability, and resources to effectively engage consumers, including, as appropriate, the inclusion of lived experience team members.

- Ensure their research plan includes appropriate timelines to plan and support consumer involvement activities.
- Ensure their research budget includes costs associated with supporting consumers (e.g., consumer engagement managers, translators, interpreters), supporting consumer involvement (e.g., travel costs/regional trial sites for rural and remote populations), consulting with consumers (e.g., events), and appropriately remunerating consumers for their time and contribution.
- Ensure their risk management plan addresses consumer involvement in the planned project, including provision of effective support.

To achieve best practice consumer involvement, MRFF-funded projects/grantees and their supporting research organisations would:

- Build and maintain ongoing relationships and partnerships with consumers and consumer organisations.
- Ensure consumers are involved in the project at least as effectively as outlined in the grant application.
- Ensure researchers and consumers are clear on their roles and responsibilities.
- Provide effective support, training, and information to consumers, including using plain language, culturally appropriate concepts, and with awareness of any sensitivities particular to that consumer group, to allow consumers to contribute to their full potential.
- Provide an environment where consumer involvement is safe, sensitive, and respectful.
- Ensure sufficient consumer numbers to facilitate multiple voices and peer support amongst consumers.
- Maximise return on investment by ensuring outcomes of research are shared (including through publication, but also through feedback to the community, health services, and policy makers), and, where appropriate, translated into practice.
- Ensure all consumers involved in the project receive regular feedback and updates on the results and outcomes of the project, including the value they have added.
- Appropriately compensate and recognise consumers and community members for their involvement.
- Ensure consumers are appropriately acknowledged in reports, presentations, etc.
- Reflect and evaluate with consumers to inform continuous improvement.
- Use progress and final reports to report on consumer involvement in their project.

Resource 6: What are you doing to involve people?

How are the public involved in your work? Who is doing which tasks? This is an action-based approach to the spectrum of involvement, designed to aid discussion about **assessing current involvement and planning for future activities.** The pyramid gives an indication of how many people might be involved in each action.

Actions	Involve people by…
Innovating This includes prototyping, piloting, establishing, and creating new ways of doing things. This can include anything from building partnerships or buildings.	**Supporting them to:** ● Design and carry out research ● Create solutions ● Implement ideas ● Learn from actions
Managing, delivering and evaluating Working in partnership to manage ongoing activities.	**Having:** ● Clear roles and tasks for the public ● Elections and interviews when appropriate ● Clear and accessible accountabilities for all roles (including staff), groups and committees. **Asking them to take actions such as:** ● Managing or overseeing actions, processes and procurement ● Directly delivering services or reviewing providers ● Evaluating actions, processes and outcomes
Prioritising and planning Working in partnership to prioritise actions and plan implementation.	● Agreeing priorities in a clear, transparent way (this can include stopping certain actions) ● Having clear accountabilities for planning at all stages ● Having a transparent and adaptable budget
Listening, responding and acting Actively seeking feedback, responding to ideas, compliments and complaints with actions.	**Asking them to help:** ● Interpret feedback ● Influence responses to ideas, compliments and complaints ● Asking for ideas for actions This includes telling people what this action was, particularly those who have given feedback.
Asking and discussing Asking people what they think, need and want and discussing it with them.	Inviting people from your intended audience or people you are trying to help to: ● Design **how** you will collect feedback and **interpret** the results ● Identify any potential barriers that might stop people from giving feedback.
Telling Giving information about what you have done, are doing or are going to do.	● Sharing opportunities to be involved ● Asking people for ideas and support to share and disseminate what you want to tell people ● Ask for feedback about how you are sharing information and attempt to measure the impact.

The graphic 'What are you doing to involve people?' is adapted from a resource created by Jack Nunn (2014) and is licensed under a Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International License

Resource 7: 'Public', 'Community', 'Consumer' or 'patient' involvement?

There are many things to think about when involving the public in research – starting with asking what words people prefer to use to describe themselves. This document is intended to help ask the right questions for the right roles.

How to use this resource: Under 'Assumptions and barriers', read the questions and consider if these might be barriers to involving some people, and consider how you might overcome these. 'Learning needs and support' examines the role in more detail and asks questions about the support people might need support to develop.

Be clear what you want– which stakeholders do you want to involve? Is it someone with specific experiences or skills? Is it someone with a lay perspective or just anyone who can give their time? Consider who you might unintentionally exclude by using these terms and be clear what **you** mean by *engagement* or *involvement*.

Assumptions and barriers	Role Description	Learning needs & support
• What commitment do you expect (time/financial implications) • Have you asked people to think about their emotional readiness? • Do you expect them to be reading and writing information and documents? Have you considered what formats might be appropriate? • Are you assuming a good ability to speak and read English? • Do you expect a certain educational background?	**Public/Community/Lay Leader:** A person who speaks and acts on behalf of all members of the public or specific communities, and takes a leading role in representing other lay representatives. The role may involve holding people or organisations to account. **Public/Lay representative:** a member of the public (not a professional) who is a representative. They must speak and act on behalf of others (including people with specific experiences). They may be guided by lay leaders but will be expected to take direct action to ensure that they are informed and able to represent the views of others.	**How are they supported to be a representative?** • How will they be gathering views? • Will this involve research? • Do they have a budget? • Should they be paid? • Is there admin and practical support (from an organisation?) • Is there any training available? **Who is already doing this?** • Are there any opportunities for them to be involved in peer support or have or be a buddy? • What can be shared with other organisations? (E.g. learning, resources) **How are people involved?** • Can people be involved in other ways? (e.g. is it face to face meetings? What can be done online, what cannot?)
• Are the people who have engaged with you the only people who might be interested?	**Interested and engaged members of the public:** People who know about and/or are interested in decisions being made, but may take no direct action other than giving feedback, being involved in a public dialogue or signing petitions.	**Could there be a need for translation?** • Are there any groups or organisations who could support with this? **Remember**: 'public dialogue' is not fully 'representative' but can give a strong indication of how the public at large feels
• It is easy to assume that people who are not engaged don't want to be. • Often they won't even know how they can contribute or be involved • Some may not be able to afford the time, caring responsibilities or travel.	**Uninformed, disengaged or disinterested members of the public:** people who, for what ever reason, are not engaged, informed or interested in influencing decision making or shaping the future of health and social services.	**A majority of the population are in this category.** • What information or support might some people need to help engage them or move them into other roles? • What might make people move back into this role? (e.g. not seeing direct improvements, or too much of organisational change?)

Remember: roles are not always fixed, they are often just a way of articulating different things people can or should do. Tasks can be more focused. There is always a way for dedicated people to give their time and develop their skills, what ever the label or role description

Resource 8: Ethics and involvement

Who decides who decides what is ethical?'

- Concepts such as 'involvement', 'ethics', 'democracy', 'integrity' and 'inclusion' cannot be easily defined, as they carry resonances of concepts such as **equality**, **justice** and certain '**rights**'
- At the root of the word 'ethics' is not one single definition, but an entirely subjective concept, expressed in English by the words 'fairness' or 'justice'
- Translating such descriptions between cultures and languages presents difficulties

In Australia, the 'National Statement on Ethical Conduct in Human Research' guides research conducted in Australia.[2]

Ethical involvement – why?

The Health Research Authority UK in partnership with the National Institute of Health Research published a briefing on the evidence for how public involvement can have an impact on research, and how public involvement in research can support the ethical review process by helping to:

- **make research more relevant** – so that the research results are more likely to benefit patients and the public
- define what is likely to **be acceptable** to participants – particularly in controversial or sensitive research
- **improve the informed consent process** – making it easier for prospective participants to understand the research and its potential risks and benefits
- **improve the experience of participating in research** – checking that the practical arrangements for participants are appropriate and a respectful use of people's time
- **improve the communication of findings to participants and the wider public** – providing information on the progress of the research as well as the final results.

Adapted from: https://www.hra.nhs.uk/planning-and-improving-research/best-practice/public-involvement/

Grey area alert!

Differentiating between public involvement activities and qualitative research methods is complex – **seek guidance if you are unclear if additional ethics approval is required:** "Engaging the public as research participants and treating their verbal contributions as data would always, in our minds, necessitate the gaining of ethical approval. This would, we believe, also apply if the information gained from consulting the public in the research design stage is presented as qualitative research data"

Extracts from: "A framework for public involvement at the design stage of NHS health and social care research: time to develop ethically conscious standards" Pandya-Wood, R., Barron, D.S. & Elliott, J. https://doi.org/10.1186/s40900-017-0058-y

2 https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2023

Aboriginal Health and Medical Research Council (AH&MRC) ethical guidelines

Summary of Five Key Principles

The Aboriginal Health and Medical Research Council (**AH&MRC**) ethical guidelines. See also Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) Code of Ethics

- Ensure net benefits for Aboriginal people and communities (including co-designing the research)
- **Aboriginal Community Control of Research** (ensure involvement, Aboriginal oversight and meaningful engagement at all stages of the project, support and that consent has been sought
- Cultural Sensitivity
- Reimbursement of costs
- Enhancing Aboriginal skills and knowledge

Adapted from: https://www.ahmrc.org.au/wp-content/uploads/2020/06/V2.0-Key-principles-Updated.pdf

International best-practice on ethical involvement - when and how?

- "Researchers who conduct studies in health and social care are encouraged to involve the public as early as possible in the process of designing their studies"
- "The process of ethical review does not consider how researchers work with patients and the public early on to design their studies"
- "there is no requirement for researchers to seek ethical approval for public involvement"
- "the ways in which researchers involve the public in the design of their studies are sometimes unintentionally unethical"

Extracts from "A framework for public involvement at the design stage of NHS health and social care research: time to develop ethically conscious standards" Pandya-Wood, R., Barron, D.S. & Elliott, J. https://doi.org/10.1186/s40900-017-0058-y

What is ethical research and what is ethical involvement?

The question of what is ethical research conduct, and what does ethical involvement in research look like is complex and ongoing – the diagram below seeks to articulate a flow chart to help work through the stage of the research, and if formal ethics approval from a Human Research Ethics Committee is needed for the planned method of involving people.

What is ethical research?
Public involvement in deciding and overseeing what is ethical
Ethical public involvement in the research
Best practice public involvement requiring no additional approval
Best practice public involvement which requires ethics approval
Qualitative methods inform research

Do I need ethics to involve people?

The shortest answer to this question is – **if you're not sure, seek guidance from ethics advisors**. In Australia, all human research must be conducted in accordance with the 'National Statement on Ethical Conduct in Human Research 2023' (always check this is most up to date version!).

What does 'best-practice' ethical involvement look like?

Whatever methods of involvement are being used, and whether or not formal ethics approval is required, the following are important considerations to ensure the involvement method aligns with best-practice:

- How have you involved different stakeholders in helping design your involvement plan?
- When recruiting people to be involved, is your method appropriate and inclusive?
- Is what is being asked of people involved reasonable (time-commitment, work-load, emotional considerations)
- Is your method of involvement inclusive? Are people supported to be involved? Are people paid for their time? If not, why? Are people paid for travel? Will people be provided with IT equipment and internet access? Will they be offered training and emotional support?
- Do you have formal documentation clarifying people's tasks, commitments and expected conduct (including any relevant legal documentation such as confidentiality agreements)?
- Have you asked for people's preferences about ways of working? Have you asked if people would like their involvement to be anonymous or attributed? Will they be invited to be co-authors or presenters of the research?

Resource 9: Questions to ask about research

Questioning everything is at the root of the scientific method, that's what gives us knowledge. Good research attempts to answer questions using a rigorous method to give answers (or more questions!). **Critical appraisal** is a way of looking at published or reported research and asking questions about the validity of the methods, the results and how published findings can be acted on. Below are some basic questions to ask of any research before it moves on from the design stage. When answering these questions, try to start with what is good, and then move onto what could be improved.

Ethics – Are the participants being recruited in an acceptable way? Is it possible to have informed consent? Are participants paid and is this relevant? Are participants exposed to unnecessary risk? Are the exclusion criteria appropriate or too excessive? (e.g. gender, age or being pregnant are common exclusion criteria)
Need – Does the research question address something of importance to the public and patients? Does it look at clinical need or an uncertainty about current treatment or services?
Public involvement – Do you think the public have been involved in identifying the need for the research, the design of this research or any other stages? Is there any budget for public involvement? Is there any evidence of public involvement?
Research method – is the research question clear? Is the method valid? Do you need more information to answer these questions? Is the research new or has it been done before (e.g. has a systematic review been done)?
Translation – is it clear how this research could be useful? If not, how could it be better explained?
Research Funding – Who is paying for this research, is there a conflict of interest? Is the cost of this research justifiable when compared with other priorities? Who owns the findings, data and the results (e.g. intellectual property)?
Dissemination - Will the results and data be published? Will this be publicly accessible? (this may help avoid research being repeated). Will any of the successes of involving the public be shared?

___

The questions below can be more helpful to ask for clinical research:
Patient experience – what issues might there be? Will this potentially improve the experience of future patients?
Information – How is information presented to potential participants? What is good, what could be improved? How could information affect the ability to give informed consent? Are the risks and benefits clear? Is the timescale and commitment clear?

For more detailed information on critical appraisal, find some free resources from the Critical Appraisal Skills Programme at:
http://www.casp-uk.net

Resource 10: The 6Rs

When working with others in a group or on a project, it can be helpful to make sure the following are as clear as possible:

Remit

- What is the purpose of the meeting/group?
- Are there any terms of reference? Does everyone have a copy?
- When they were last revised? Are they updated regularly?

Role

- Is each member clear about why they are there?
- What are people's expectations of you?
- Do you or others ever find that you have conflicting roles?
- What do others expect of you?

Representative

- Are you seen as a representative?
- If so, who are you supposed to represent? Do you have a constituency, a group of people whose views you aim to represent?
- How are you supported to be a representative? How might you gather people's views? How do you report back to them?
- Are you there because of a personal experience?

Responsibility

- What responsibilities do you or others have? (see terms of reference)
- Who sets the agenda? Is this responsibility shared?
- How are decisions made? How are they implemented? Who takes responsibility for reporting back and ensuring the wishes of the group are carried out?

Relationships

- Does it feel like being part of a team, everyone working together?
- Is there a sense of common purpose and goals?
- Do you get along with each other? Do you know each other as individuals or are you strangers brought together by your roles?

Readiness

- Are you ready to get involved? Have you considered your emotional readiness and any time commitments?
- Have you received any training to help you prepare for your role? Have you thought about how can you maintain and support your wellbeing?
- Do you know who or where you can go to for support regarding any of these issues?

Resource 11: Answering important questions using Maslow's 'hierarchy of needs'

Maslow's hierarchy claims that needs that are **low** in the hierarchy must be partially satisfied before needs that are **high** in the hierarchy can be prioritised. Think of a hierarchy as a pyramid, 'low' meaning a basic foundation.

The answers to the questions on the left lie at the very heart of good meetings. They've been placed in an order approximate to the hierarchy. Discuss whether you agree with the questions being placed with the associated needs?

1. Will this be a good use of my time? 2. Why are we meeting anyway? 3. Are we going to accomplish something? Will this meeting help me make a difference?	**Self Actualisation** To find self fulfilment and realise one's potential
4. Will we stay on the topic or go off at a tangent?	**Creative needs** To create symmetry, order, and beauty
5. Is there an agenda?	**Cognitive needs** To know, learn explore, find out
6. What's expected of me? 7. What happened as a result of the last meeting? 8. Will we be making decisions and if so how?	**Esteem needs** To achieve, to be competent, gain approval and recognition, self-confidence, independence
9. Should I be here? Am I welcome? Do I feel I am being treated with respect?	**Belongingness and love** To be loved, liked needed or accepted by others
10. Where are the fire escapes? 11. Who are the other people?	**Safety needs** To be free of danger physically and emotionally – a sense of security
12. When will we take a break (e.g. to go to the toilet)? 13. Where is the food? When will we eat? 14. How long will this take? When are we leaving? (Will I need a strong coffee or a sleeping bag?)	**Physiological needs** Food, water, shelter, sleep, excretion

Questions adapted from Roberta's Rules of Order by Alice Collier Cochran Published by 2004.

Resource 12: How can involving patients improve 'basic' research

'Basic' research can be thought of as 'foundational' – exploring knowledge that is the basis for all other discoveries and research – it does not mean it is simple!

How can Patient Involvement enhance Basic Research?

Greater relevance
Involving patients ensures that researchers demonstrate accountability to people with arthritis and that the work being undertaken has the greatest relevance.

Stronger funding applications
Applications reviewed or written by patients clearly illustrate aims, patient benefits and study importance to all reviewing committee members.

Improved communication
Engaging with a new audience and more people will improve verbal and written communication skills – practice makes perfect!

Motivation and focus
Hearing from people living with arthritis and what the difference research makes to their lives will provide an extra level of motivation.

Novel perspectives
Involving patients in research brings new insight and perspective to the table that basic researchers don't routinely hear.

Increased recruitment
Patients can increase sample donation and the retention of crucial donors by helping to write accessible, engaging patient information and devising patient sensitive study designs.

New ideas
Talking to wider groups of patients, particularly at early stages of research, broadens the field of influence thus generating novel challenge, discussion and ideas.

Public interest and engagement
Patients involved and invested in studies are excellent research advocates and can generate more interest from the general public.

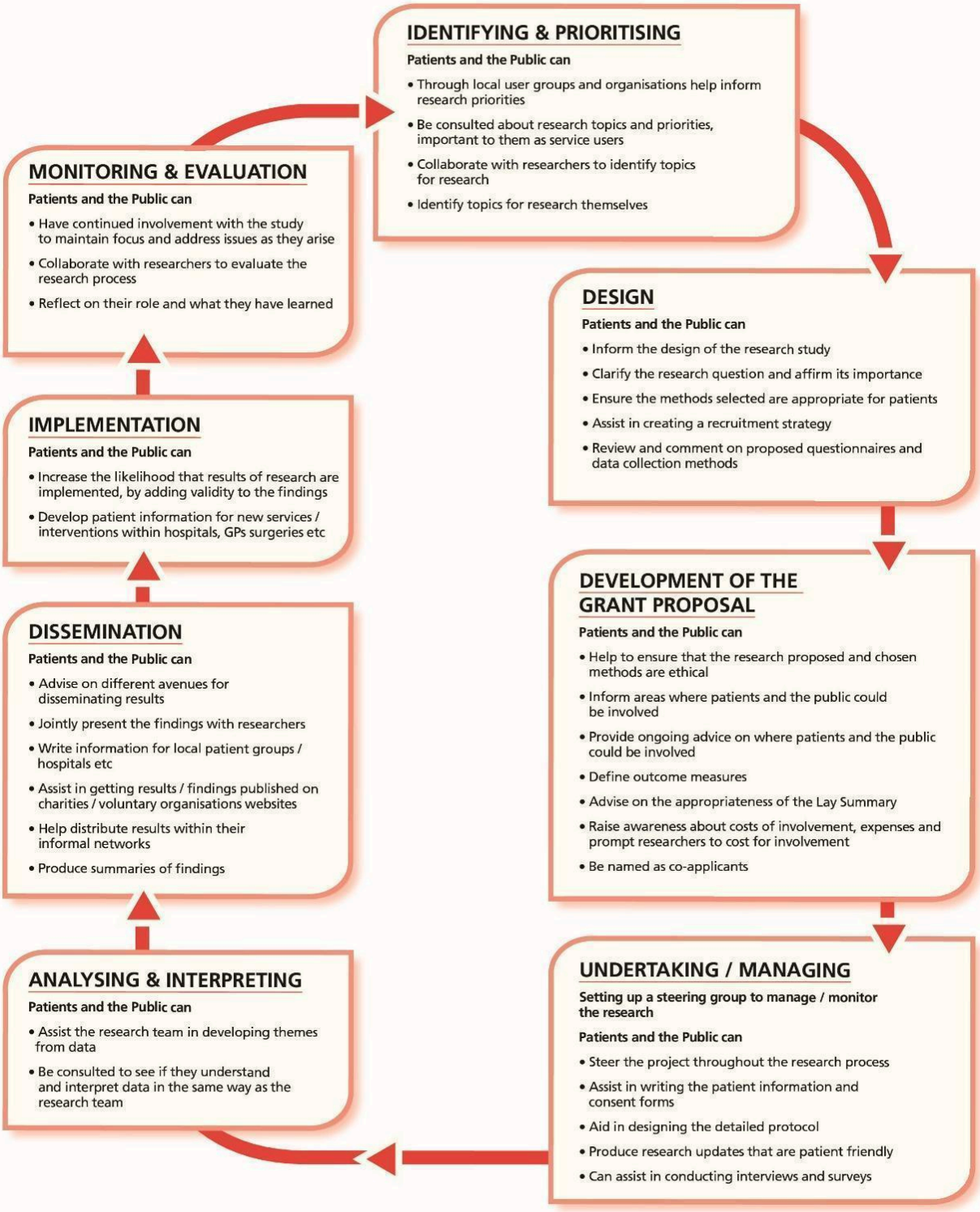
Greater impact
Studies have shown that carefully considered involvement activities make for more impactful research.

Taken from 'Patient and Public Involvement – a Researcher's Guide (Versus Arthritis)' [3]

[3] https://www.arthritisresearchuk.org/research/news-for-researchers/2017/july/patient-and-public-involvement_a-researchers-guide.aspx

Resource 13: Public involvement in the research cycle

How to incorporate patient and public involvement in the research process


IDENTIFYING & PRIORITISING
Patients and the Public can
• Through local user groups and organisations help inform research priorities
• Be consulted about research topics and priorities, important to them as service users
• Collaborate with researchers to identify topics for research
• Identify topics for research themselves
DESIGN
Patients and the Public can
• Inform the design of the research study
• Clarify the research question and affirm its importance
• Ensure the methods selected are appropriate for patients
• Assist in creating a recruitment strategy
• Review and comment on proposed questionnaires and data collection methods
DEVELOPMENT OF THE GRANT PROPOSAL
Patients and the Public can
• Help to ensure that the research proposed and chosen methods are ethical
• Inform areas where patients and the public could be involved
• Provide ongoing advice on where patients and the public could be involved
• Define outcome measures
• Advise on the appropriateness of the Lay Summary
• Raise awareness about costs of involvement, expenses and prompt researchers to cost for involvement
• Be named as co-applicants
UNDERTAKING / MANAGING
Setting up a steering group to manage / monitor the research
Patients and the Public can
• Steer the project throughout the research process
• Assist in writing the patient information and consent forms
• Aid in designing the detailed protocol
• Produce research updates that are patient friendly
• Can assist in conducting interviews and surveys
ANALYSING & INTERPRETING
Patients and the Public can
• Assist the research team in developing themes from data
• Be consulted to see if they understand and interpret data in the same way as the research team
DISSEMINATION
Patients and the Public can
• Advise on different avenues for disseminating results
• Jointly present the findings with researchers
• Write information for local patient groups / hospitals etc
• Assist in getting results / findings published on charities / voluntary organisations websites
• Help distribute results within their informal networks
• Produce summaries of findings
IMPLEMENTATION
Patients and the Public can
• Increase the likelihood that results of research are implemented, by adding validity to the findings
• Develop patient information for new services / interventions within hospitals, GPs surgeries etc
MONITORING & EVALUATION
Patients and the Public can
• Have continued involvement with the study to maintain focus and address issues as they arise
• Collaborate with researchers to evaluate the research process
• Reflect on their role and what they have learned

Adapted with kind permission from Patient and Public Involvement in Health and Social Care Research: A Handbook for Researchers by Research Design Service London

Resource 14: Example Terms of Reference for a Stakeholder Reference Group

This resource is a template for a Stakeholder Reference Group, and is purposefully detailed. You might only need to adapt sections of this - it has been included in full to aid discussion.

Plain language summary

We are inviting people to join a group to help us run the ([INSERT NAME]) project. This research project is seeking to understand what is important to people affected by [insert relevant term], and how we can improve the way we measure what is important. The group will be a mixture of people affected by [insert relevant term], researchers and people who work in relevant industries (for example, businesses that care for people with [insert relevant term]).

By bringing together all of these people into one group, we hope to improve the quality, relevance and impact of this research project. Members will be supported to take part in the group, including by being given relevant training and offered payment for their time and expertise. We will offer support to help ensure we are as inclusive as possible. We will also involve all members in helping us evaluate and improve our ways of working.

The group will mostly discuss and decide things using online tools (including online text-based discussion forums, shared online documents and audio/video teleconference meetings). We may also organise some in-person events (with an option to join online), and will support members to attend those in the way that suits them best.

Establishment

The **[insert name]** Interim Stakeholder Reference Group was established on [date]. The **[insert name]** will transition to the [not interim] Stakeholder Reference Group by [insert date] after an approval vote by all members.

Nature

A reference group consisting of people representing a number of defined communities, who provide advice to the international research team (led by organisation X) on the development and implementation of [insert] research project.

Purpose

The **[insert]** project aims to identify a **suite of outcome measures** that are aligned with stakeholder goals and develop **guidelines for implementation** to ensure that Australia's efforts to improve the lives of people living with [insert relevant term] are unequivocally realised. The purpose of the [INSERT NAME] Stakeholder Reference Group ([INSERT NAME] iSRG) is to provide advice from multiple stakeholders on the planning, design, implementation and evaluation of the [INSERT NAME] research project. This advice will help ensure the research project is acceptable, appropriate, accessible, equitable and culturally safe.

The [INSERT NAME] Project is funded by [insert funding details] The project brings together an international team of experts in [insert relevant term], core outcomes measurement, stakeholder engagement and impact measurement and evaluation. The project is administered by [insert organisation] and led by [insert project lead].

Scope

The [INSERT NAME] Interim Stakeholder Reference Group ([INSERT NAME] iSRG) provides non-binding advice to the research team. The [INSERT NAME] iSRG will have the authority to consult and engage non-reference group members on an ad hoc basis as it considers necessary, and upon approval by the lead investigator. Where appropriate, a budget for such consultation and engagement will be determined by the lead investigator.

The [INSERT NAME] iSRG will align work with [other relevant working groups].

Conduct

The [INSERT NAME] Project research team is committed to providing an environment free from all forms of unlawful discrimination, harassment, bullying, vilification and victimisation. Members of the [INSERT NAME] iSRG will act in accordance with [insert organisation]'s policies on 'Equity and Diversity'. The desire for research activities to be inclusive, simple and accessible to all stakeholders will be at the core of decision-making. Where necessary, additional support will be provided by the research manager to assist stakeholder with navigating [INSERT ORGANISATION]'s processes and those of other relevant organisations. Everyone involved in the work of the [INSERT NAME] iSRG will be treated with courtesy, and respect and everyone should act with integrity[1].

Support

[insert organisation] provides secretariat support for the group and will take responsibility for coordinating the induction, on-boarding and training of members.

Tasks of the secretariat will include:

- Finding dates for meetings and training, and sending invites
- Organising meeting spaces (online and in person)
- Organising any travel or practical support required for people to attend
- Ensuring all members have been sent the information (documents etc) required in time for meetings and instructions for giving feedback
- Ensuring all members of the research team have received relevant feedback from SRG members

A facilitator (insert name) will support the work of the [INSERT NAME] iSRG, as described in the section 'Ways of working'. Remuneration will be offered to [INSERT NAME] iSRG members in accordance with [insert organisational documents relating to finances, privacy and other relevant policies].

Any support members require in order to participate (including practical support, financial support, IT skills development, knowledge development) will be assessed using a learning and support needs assessment survey. Support will be provided within the scope and budget defined in this document.

The scope of technical support available is defined in the section 'Technical Support'

Tasks

Members will contribute a combination of their own personal experience and, where appropriate, learning from research, to the activities of the iSRG. This will include supporting with consultation activities with the public (such as survey design) and other relevant stakeholders to inform the [INSERT NAME] research team.

Members will be involved in monitoring and evaluating the implementation of the [INSERT NAME] research project, as well as identifying and implementing mechanisms for continuous improvement, with a particular focus on improving equity.

A transparent feedback process will be established between the iSRG and the research team via a feedback register. The register will be accessible to all iSRG and research team members and will include feedback / advice provided by the iSRG, the date of the advice, the date the advice was provided to the research team, and any actions / responses related to the advice.

The tasks of the [INSERT NAME] iSRG group are further described under the following headings.

Research

Members will work with the [INSERT NAME] research team and other relevant stakeholders to:

- identify and refine research questions
- co-design research activities

- commission, conduct and lead research (for example, gathering the views of people affected by [insert relevant term])
- evaluate the [INSERT NAME] research project (including impacts and outcomes)
- ensure the research project is conducted according to the NHMRC Collaborative Research Guide[4]
- report on the [INSERT NAME] research project (including contributing to peer-reviewed publications)
- disseminate learning and assess knowledge translation.

Members will be invited to provide feedback and advise on planned research activities of the [INSERT NAME] research team, including data governance and access. The lead investigator will provide information to the [INSERT NAME] iSRG (at least once a year) on research budgets in order to inform planned research and potential partnership activities.

Sharing data on best practice

Members will foster networking, information sharing, two-way communications and collaboration with University of Queensland partner organisations and other relevant stakeholders (including organisations and individuals). The group should seek to work across [insert organisation] and other relevant partner organisations in order to align communications with similar groups at both state and national levels (and at international level where appropriate). The purpose should be to share best practice and learning, promote mutual support and share data (standardised where possible) on activities, outcomes and impacts in order to inform both the work of the [INSERT NAME] iSRG and any future involvement of the public in [insert relevant term] care and services evaluation[1–3]. This includes, but is not limited to contributing to 'Standardised Data on Initiatives' (STARDIT) reports in order to share data about outcomes and impacts from the work of the [INSERT NAME] iSRG[3,4].

The [INSERT NAME] iSRG should work to establish a community of practice with other similar groups and at least two members of the [INSERT NAME] iSRG should sit on other relevant groups in order to facilitate communication and shared learning.

Learning and development

Regularly assessing the learning and development needs of the [INSERT NAME] iSRG, the wider [INSERT NAME] research team, and other stakeholders is essential in order to ensure the activities undertaken during the [INSERT NAME] Project are acceptable, appropriate, accessible, equitable and culturally safe. At least once a year the [INSERT NAME] SRG members will review both internal and external learning and development needs and identify any training priorities and other relevant initiatives.

- **Internal** - learning and development needs for group members should be identified by the group at least once a year, with a discrete and transparent budget assigned to the learning and development needs of the [INSERT NAME] iSRG. The [INSERT NAME] iSRG will make recommendations on spending to the lead investigator that identify the learning and development opportunities that the group has decided are necessary.
- **External** – through its work, the [INSERT NAME] iSRG will identify the learning and development needs of relevant stakeholders, including the general public (community members, health and care professionals, researchers and other stakeholders)[5]. The [INSERT NAME] iSRG will make recommendations on spending to the lead investigator. The intent of external learning and development activities is to ensure the evaluation methods for [insert relevant term] care and services are acceptable, appropriate, accessible, equitable and culturally safe.

[4] https://www.nhmrc.gov.au/file/14916/download?token=D6icKXqA

Ways of working

The [INSERT NAME] iSRG will work in a way which is inclusive and accessible, with the ways of working reviewed annually by the [INSERT NAME] iSRG in partnership with the [INSERT NAME] academic research team.

Information will be shared with members using secure online tools such as email and document sharing.

Communication between the group

The following online tools will be used by the group to communicate:

- **[INSERT online platform being used]**: The main forum for discussion and decision making is on a private [INSERT online platform being used] group. Communication within this is private and should not be forwarded to anyone outside the group without the permission of every member.
- **Document sharing platforms**: When appropriate, these will be used for co-writing/editing and commenting.
- **Email**: The number and length of emails will be kept to a minimum, with 'reply-all' discouraged, in favour of using the [INSERT online platform being used] discussion space. Emails will be used to remind people about online meetings, online discussions and any outstanding actions.

Additional online tools may be adopted by the group, for example, establishing an informal Whatsapp chat group or using SMS reminders

Sharing outside the group

The [INSERT NAME] project will have a number of publicly accessible information outlets, including a website and social media channels. SRG members will work with the [INSERT NAME] team to agree how and when information will be added to these public channels. Individuals involved in this work should seek guidance from the [INSERT NAME] team if they are unsure what they can share using their own communication channels outside the group (including sharing n social media and forwarding communications).

Discussions

In order to ensure people can participate in discussions in a flexible way (for example, people with caring responsibilities), required discussions will take place where possible using asynchronous (not in real time) online text-based discussions, with time parameters ensuring people have enough time to read, comment, consider others' comments and reflect[6]. Online text-based discussions will last for a minimum of one week.

Discussions will be facilitated by a neutral person, who is paid for their time by [insert organisation]. The facilitator will:

- moderate any discussions (online or face-to-face) to ensure they are inclusive and align with [insert organisation]'s relevant equity policies
- be responsible for liaising with relevant staff from [insert organisation] in order to organise and maintain both face-to-face and online discussions.

Meetings

In order to be as inclusive as possible (in particular to members from regional areas and those with different cognitive processing abilities), real-time (synchronous) discussions will be limited where possible. When such meetings are necessary, they will be conducted online where possible, with in-person attendance optional (in addition to aligning with any relevant COVID-19 restrictions), and any in-person events always having an option to join online (hybrid).

Required documents will be shared in advance, with a minimum of one week to read documents before a meeting and no more than one hour of reading and preparation required for each meeting.

Synchronous meetings will be held at least every 6 months, with dates agreed at least six months in advance.

Face to face and online meetings will be organised by the [INSERT NAME] Secretariat.

Moderation and facilitation

The online forum and any meetings will be moderated and facilitated by Jack Nunn, supported by staff from [insert organisation]and [INSERT ORGANISATION]. The facilitator will ensure that discussion remains within the agreed boundaries defined in this document. The tasks of a facilitator are to:

- ensure everyone understands how to access the discussion (supported by the Secretariat to share relevant joining information)
- Start and close discussions
- Introduce yourself at the start and encourage everyone to do the same
- Make everyone feel welcome
- Involve everyone in agreeing boundaries and how they will be managed
- Ensure that people understand how they will be kept up to date with the discussion
- Attempt to include everyone equally in discussions
- Thank someone the first time they contribute
- Seek clarity when required, asking open questions where possible

See the section ‘What is moderation and facilitation?’ in the appendix for more information.

Participation

Members will be expected to actively participate in discussions and meetings through:

- attendance at meetings (either virtually or in person)
- text-based online discussion
- commenting on documents
- reviewing meeting notes, papers and other relevant documents

While it may not be feasible to participate in every meeting or discussion, members are expected to participate in at least half the iSRG activities, including voting procedures.

The facilitator will review attendance every 6 months and in consultation with the study team, may put in place a remediation strategy should a member not meet these expectations.

Reviewing ways of working

The [INSERT NAME] iSRG and the lead investigator will review all ways of working at least once a year, including evaluating the effectiveness of these ways of working, with particular attention paid to equity and inclusion.

This will include (but is not limited to):

- a survey of members to capture feedback on effectiveness, procedures, terms of reference and membership
- a review of the composition of the group will be undertaken annually to ensure that the membership is appropriate to the group’s roles and responsibilities
- recommendations for changes to the Terms of Reference or membership, with the results provided to the iSRG for approval and the [INSERT NAME] research team for noting

- an independent report by the facilitator, including an assessment of the ways of working and any recommendations for changes, and relevant input from the Secretariat on improved ways of working relating to the functioning of the group
- the [INSERT NAME] iSRG will be convened until 31 December 2023 to coincide with the term of the current grant, after which time the group will review any next steps regarding disbandment or transformation.

Membership: experience and expertise

[insert organisation] values diversity, supports and promotes equity, good access to decision making and broad representation on its groups, reflecting the communities we serve, including the public and other stakeholders. Diversity in all its forms will be considered, including (but not limited to) gender, sexuality, neuro-diversity, culture and language, access needs, education, socioeconomic status, advocacy experience, professional and personal experience.

Anyone can be a member of the [INSERT NAME] iSRG, as long as they can be supported to meet the essential skills requirements (see below). The group should have between eight and fifteen members, and at any one point, membership should consist of at least four people who identify as being a part of at least one of the following defined communities of shared interested:

- having an experience of using [insert relevant term] care and services in the last 10 years
- having an experience of being affected by [insert relevant term] (including parents, loved-ones and carers of people with [insert relevant term])
- having an experience of being affected by a rarer or less common form of [insert relevant term] (including parents, loved-ones and carers of people with [insert relevant term]).

Members will be representatives from these communities, and expected to speak from either personal experience, or where appropriate, formally work with these defined communities in order to gather views.

In addition (and these need not be exclusive of the defined interests above):

- at any one point, at least one person who identifies as Aboriginal or Torres Strait Islander should be a member, preferably with an experience of being affected by [insert relevant term]
- at least two people with a professional experience of being a [insert relevant term] researcher or health professional should be a member of the group, with the task of advising the group from a professional perspective[5]
- at least two people with professional experience working in [insert relevant term] care.

Membership terms will last for two years, with planning to ensure overlap between incoming and outgoing members if the project extends beyond this time period. Membership will be reviewed annually by the [INSERT NAME] iSRG in consultation with the [INSERT NAME] academic research team, in order to ensure that people from defined communities are represented.

Essential skills requirements

While every effort will be made by the research team to ensure the [INSERT NAME] iSRG is inclusive, the following skills have been deemed essential in order to participate effectively as a member:

- to be able to comprehend spoken English or Auslan
- to be able to read and write in English to a level which allows full participation as a member
- to be able to use internet connected devices (such as computers and smart phones) in order to use online communication tools such as voice and video-conferencing, online text-based discussions, document editing tools and secure messaging such as emails.

Where possible, the research team will provide appropriate support in order to ensure anyone can be supported to achieve these essential skills.

Recruitment plan

Recruitment to the [INSERT NAME] iSRG should be a transparent process[7], with the public and other stakeholders involved wherever practicable. A more detailed version of this plan will be shared in future documentation, and it is divided into four stages:

Stage	Summary
1: Establish Interim Group	[INSERT NAME] research team staff appoint interim [INSERT NAME] iSRG facilitator, and between 2-4 other members (from the defined communities of shared interest where possible)
2: Co-refine documentation	Work with [INSERT NAME] research team and [INSERT NAME] iSRG facilitator to co-refine all documentation with the group, including stakeholder mapping, recruitment plan and a preliminary knowledge and skills assessment. Finalise recruitment plan for approval by [INSERT NAME] research team, including any required budget and the application and selection process.
3: Share Invitation	Share information about the [INSERT NAME] iSRG on relevant websites and other appropriate channels in accessible Plain English documents, including information about the application and selection process.
4: Select and induct	Selected [INSERT NAME] research team members and [INSERT NAME] iSRG assess applications (with appropriate support from secretariat). Invite new [INSERT NAME] iSRG members, and induct with appropriate training and support.

Committee structure

[insert diagram]

Representative member and how they are appointed

Potential members will complete an application, with the selection process conducted jointly by the [INSERT NAME] iSRG and selected members of the research team. If selected, the member will be appointed for a two-year term. The maximum term will be three years. When a member's term expires, the [INSERT NAME] iSRG can:

- nominate a member to remain on the [INSERT NAME] iSRG as an Additional member, though the final decision on the appointment of Additional member lies with the lead researcher
- nominate a new member to replace any member standing down.

Representative members are voting members, and are actively supported to represent the views of others from the stakeholder groups they represent.

[Remuneration?}

Additional members and how they are appointed

Additional members will be identified via nominations from the research team, the [INSERT NAME] iSRG, or other appropriate mechanisms. If selected by the [INSERT NAME] iSRG, Additional members will be appointed for a two-year term, renewable for a further three years in accordance with [INSERT NAME] iSRG needs and status of group membership at the time. The group will consider Additional members based on skills, experience or project-related expertise.

Additional members are non-voting members, and are invited to share their personal views and experiences with the group. Any support for Additional members will be defined in future versions of this document.

Subgroup and working groups

The [INSERT NAME] iSRG will create Working Groups as required to support specific areas of work (for example, developing a plan to involve people affected by [insert relevant term] in the research

project). Working groups will be sub-groups of the [INSERT NAME] iSRG. Each Working Group will include a Reporting member of the [INSERT NAME] iSRG. Membership of the Working Groups will be based on expertise and will not all necessarily be Representatives members of the group. The [INSERT NAME] iSRG will determine the membership, Terms of Reference and workplan for each Working Group to facilitate its efficient working. Working Groups will be disbanded when a program of work is completed.

Quorum

A quorum will be at least half the Representative members and must include at least two votes from people affected by [insert relevant term].

Decisions

A consensus will be sought for all decisions. Where consensus is not achieved, decisions will be by majority vote of Representative members. All Representative members are entitled to one vote. Where possible, all voting processes will be conducted transparently online and overseen by the facilitator, with options for anonymous voting available if deemed appropriate. The group will be given at least one week to make all decisions (including being given relevant documentation at least a week before any decision is required).

Reporting

The [INSERT NAME] Research Manager, as Secretariat, will provide reports to the [INSERT NAME] research team on iSRG activities at the research team's bi-monthly meetings. As part of such reporting, the Research Manager will bring to the attention of the [INSERT NAME] research team all matters which the [INSERT NAME] iSRG deems appropriate. In addition, the Research Manager is responsible for overseeing and delivering other data and reporting, as identified in the section 'Sharing data on best practice'.

Recording discussions

Discussions and meetings (online, voice, text-based and face-to-face) will be recorded in text documents (minutes), and will be distributed to members of the [INSERT NAME] iSRG via [INSERT online platform being used] within two weeks of each meeting. Minutes will be approved by an online vote closing approximately 2 weeks after distribution/posting.

Data management

The [INSERT NAME] iSRG will both receive and generate confidential data during its operation. SRG members must not disclose to other parties any confidential information provided by the research team (e.g. reports or data sets) or generated during discussions or meetings (i.e. the personal opinions of other members expressed during deliberations or discussions).

All confidential project data will be stored on [insert organisation' Data Management system]. Records of the iSRG's discussions, deliberations and meetings will be automatically created through the [INSERT online platform being used] platform. [insert organisation] (as the administering institution for the [INSERT NAME] Project) will be the custodians of all data generated through [INSERT online platform being used], but the platform itself will be hosted by [INSERT ORGANISATION] on their own servers (provided by X, which may store data outside of Australia).

Technical Support

Should there be a failure of the server or other functionality issues with [INSERT online platform being used], [insert organisation]has a Technical Support contact who is always on call to help with any technical issues within 24 hours. Technical support issues include:

- [INSERT online platform being used] server or forum failing to load
- Password resets or log-ins not working owing to server failure

Please note that technical support does not extend to instructions on using [INSERT online platform being used]. Detailed instructions on using [INSERT online platform being used] will be provided to [INSERT NAME] iSRG members, alongside relevant learning and development opportunities. Should technical support be required, please contact [insert contact]

Conflicts of Interest

Written declarations of conflict of interest will be submitted on appointment to the [INSERT NAME] iSRG and archived by the [INSERT NAME] iSRG secretariat. This is affirmed at the attendance of every meeting and recorded in the minutes.

Confidentiality Agreement

Written declarations of confidentiality will be submitted on appointment to the [INSERT NAME] iSRG and archived by the [INSERT NAME] iSRG secretariat. This is affirmed at the attendance of every meeting and recorded in the minutes.

Contact/Secretariat

[insert details]

Appendix

What is moderation and facilitation?

While the facilitator and moderator of a group may be the same person, the words require different tasks to be carried out.

Facilitating discussion

The word 'facilitator' comes from the Latin 'facilis' meaning 'easy'. In a literal sense, to facilitate is 'to make things easier'. Facilitators are not always subject experts, but attempt to draw on the existing knowledge of the participants, and to then 'facilitate' them to use their own skills as well as directing people to other appropriate places to continue their learning. Facilitators focus on the foundations of modern adult education:

- establish existing knowledge
- build on it and keep it relevant

Facilitators should aspire to have a neutral role, meaning whatever your personal convictions, you aspire to not support a particular position in the discussion. Naturally both conscious and sub-conscious bias may affect facilitation and facilitators may wish to disclose any discussion areas where they feel they cannot be neutral.

Facilitators should careful about attempting to establish consensus. This is almost never required – and a more effective method is to involve the group in finding and agreeing themes, grouping ideas and comments and organising the discussion. At this stage the facilitator may wish to ask the group if there are any actions or next steps that some members of the group would like to agree to. If and when consensus is required – [INSERT online platform being used] offers a number of tools which allow people to make collective decisions.

The main tasks of a facilitator include:

- Start and close discussions
- Make everyone feel welcome and safe
- Involve everyone in agreeing boundaries and how they will be managed
- Attempt to include everyone equally in discussions
- Seek clarity when required, asking open questions where possible

It is important to note that facilitation is a skill which can be developed – some people are professional facilitators – and there is always more to learn. It can be a good idea to find or establish a 'community of practice' with other facilitators in order to share learning and best practice.

Online facilitation

Facilitating discussions in asynchronous (not simultaneous) online spaces requires careful thinking about how to ensure people will remain engaged, feel welcome and be able to participate. While [INSERT online platform being used] can create an environment where facilitation can be a collective act (people tag each other in comments) – agreeing at least one person as the facilitator can help ensure the discussion is effective. A facilitator should:

- **Ensure everyone understands how to access the discussion** and see if anyone needs practical or technical support before joining
- **Introduce yourself at the start and encourage everyone to do the same.** You may wish to consider asking people to share what they hope to get out of the discussion and bring to it.
- **Ensure that people understand how they will be kept up to date with the discussion** - if it is over a period of more than a day then people may wish to have email updates
- **Thank someone the first time they contribute**. There is an art to online facilitation which requires a balance between 'lurking' (monitoring a discussion but not contributing anything) and over-contributing, the equivalent of talking too much and not creating airspace to listen

in a face to face discussion. As a rule of thumb – waiting an hour or two as a minimum for other participants to respond to a comment gives the group time – but it is essential that everyone is thanked at least for their first contributions. If someone is contributing lots and no one is responding, or if someone has said something you feel others might agree or disagree with - consider neutral comments like:

- Thank you for your comment. What do other people think?
- Thank you for that – an interesting perspective. Are there any other perspectives?

These neutral comments can be effective ways of teasing out a discussion about an area where there might not be consensus – and should hopefully avoid the facilitator revealing their own perspective and thus risking neutrality.

Agreeing Boundaries

Like any effective discussion, online discussion requires boundaries in order to function. While the facilitator introduces the boundaries and asks people to agree to them, the moderator is the person that the group agrees upholds these boundaries. Boundaries can include:

- behaving in a certain way (not harassing people)
- having an agreed topic or way of working
- having an agreed timeframe
- word limits – agreeing posts will be under a certain word length

A document called a 'terms of reference' can be helpful if the online discussion is a working group with a specific aim or purpose. If it is an online discussion, then as a minimum an initial discussion on boundaries needs to take place – which might be in the form of a document or list of boundaries and asking members of the discussion if they agree with them, have anything they'd like to add or remove.

Helpful resources

- The 'Six R's' is a good example of some questions to attempt to answer when working in any kind of group.
- Involving everyone in answering these questions can be a helpful way of establishing group working online or face to face

Moderating discussion

Moderating something means to keep it with certain boundaries. In group discussions, a moderator has the important role of attempting to do this with discussion. Effective moderation will:

- improve trust in the group discussion
- help people feel less vulnerable and possibly more willing to share views and perspectives
- protect people from abuse or harassment

As a moderator you should protect people from abuse or harassment and ensure the discussion is appropriate, within the agreed 'Terms of Reference'.

The facilitator will establish that a moderator has the permission of the group to uphold the agreed boundaries. A moderator may:

- delete messages which are outside of the boundaries agreed by the group (for example, offensive comments).
- organise the thread - merge, move or split threads (working with the facilitator where appropriate – if the role is split)
- Remind people about word limits if posts are too long
- answer participants' concerns about the forum and respond to any complaints

Administrators and Secretariat support

Administrators are not moderators or facilitators – they are usually people with specific data access permissions to grant other users more permissions. While one person may act as all three, an administrator usually can control which permissions different users have.

References for Example Terms of Reference

1. National Health and Medical Research Council, NMHRC, National Health and Medical Research Council. Statement on Consumer and Community Participation in Health and Medical Research. Health and Medical Research National Health and Medical Research Council. https://www.nhmrc.gov.au/about-us/publications/statement-consumer-and-community-involvement-health-and-medical-research. Published 2016. Accessed October 18, 2016.

2. INVOLVE. *Guide on Co-Producing a Research Project*.; 2018. https://www.invo.org.uk/posttypepublication/guidance-on-co-producing-a-research-project/. Accessed May 8, 2019.

3. Pietro L Di, Renton H, Sahhar M, Wale J, Walker C, Watson L. *An Ounce of Prevention: The Impact of Early Community Engagement on Phase 1 of the Melbourne Genomics Health Alliance*.; 2016.

4. Nunn J, Shafee T, Chang S, et al. Standardised Data on Initiatives - STARDIT: Alpha Version. 2019. doi:10.31219/osf.io/5q47h

5. Jack S Nunn, Merrin Sulovski, Jane Tiller, Bruce Holloway, Darshini Ayton, Paul Lacaze. *Involving Elderly Research Participants in the Co-Design of a Future Multi-Generational Cohort Study*.; 2020. doi:10.21203/RS.3.RS-54058/V1

6. Nunn JS, Gwynne K, Gray S, Lacaze P. Involving People Affected by a Rare Condition in Shaping Future Genomic Research. August 2020. doi:10.21203/RS.3.RS-62242/V1

7. INVOLVE. Guidance on Co-Producing a Research Project.; 2018. https://www.invo.org.uk/wp-content/uploads/2019/04/Copro_Guidance_Feb19.pdf. Accessed March 14, 2018

Resource 15: External Resources

Title	Summary	URL
Standardised Data on Initiatives (STARDIT)	Learn about STARDIT, read, edit and create reports	STARDIT.wikimedia.org.au
Key Elements of Effective Involvement	Lots of resources relating to involving people, with good content on ethics	https://healthresearchhub.com/health-and-medical-research/partnering-with-consumers/
Australian Clinical Trials Alliance – Consumer Involvement and Engagement Toolkit	An interactive toolkit, focusing on involving in clinical trials	https://involvementtoolkit.clinicaltrialsalliance.org.au/toolkit
NHMRC – Resources for Consumer and Community Involvement in Health and Medical Research	Resources for Consumer and Community Involvement in Health and Medical Research	https://www.nhmrc.gov.au/research-policy/consumer-and-community-involvement/consumer-and-community-engagement#download
Victorian Comprehensive Cancer Centre Alliance	"The Consumer Engagement Toolkit is the result of consultation with consumers and alliance members who identified a need for guiding documents to support effective engagement"	https://vcccalliance.org.au/consumer-engagement/toolkit
Cancer Australia – Consumer involvement resources		https://www.canceraustralia.gov.au/key-initiatives/consumer-involvement
National Mental Health Commission – Consumer and Carer Engagement: a Practical Guide	This guide attempts to capture the core values and principles around engagement and participation and present these in the form of a practical, good practice guide for use by mental health consumers and carers and by people working within the mental health system at all levels.	https://www.mentalhealthcommission.gov.au/lived-experience/consumer-and-carers/consumer-and-carer-engagement-%281%29
Guidelines for Community Involvement in Genomic Research		https://www.australiangenomics.org.au/wp-content/uploads/2021/06/Involve-Australia_Guidelines-for-Community-Involvement-in-Genomic-Research-1.pdf
Participatory and Inclusive Autism Research Practice Guides		https://www.autismcrc.com.au/best-practice/sites/default/files/resources/Participatory_and_Inclusive_Autism_Research_Practice_Guides.pdf

Identify topics

Prioritise topics

Commission or fund proposals

Design research

Manage research

Collect data

Analyse and interpret data

Disseminate

Implement or translate findings

Evaluate impact

Resource 17: 'LOMA Phase II clinical trial advert'

Love drinking?

Hate the morning after?

If the answer is 'yes' and you are a healthy, 14-95 year old, and do not suffer from hay fever or chronic diarrhoea **then you could help us!**

Get paid to drink as much as you can!

No hangover!

You'll help us prove we've found a **miracle cure that banishes hangovers!**

If you complete our trial* **we'll pay you** compensation of up to

$7000**

*Further trial information available on request ** Upon signing our full disclaimer document and buying our recognised insurance policy***

*** Insurance costs **only** $2500 a year

Resource 18: 'Participant Information Sheet – Phase II clinical trial'

HEPATIC – Participant Information Sheet – Phase II clinical trial

About the trial

The initial part of the trial will involve a 3-day 'party'. That's right!

We're inviting you to join us for an 'all you can drink' all expenses paid 3-day 'party'*.

What is it?

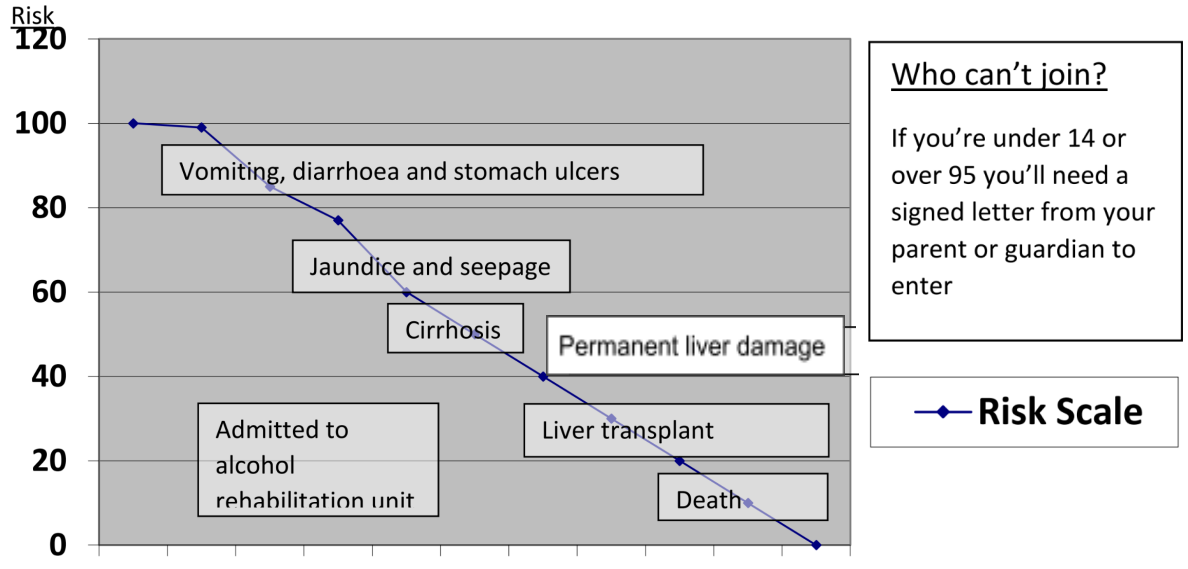
Hyper-enzyme polymerase action transmission inhibitor co-enzyme (HEPATIC) works by targeting the pathways in the multi-perplexion Maltbarely pathway. After ingestion into the alimentary canal, release through the hepatic portal vein transmits HEPATIC to the endocrine system, targeting the B52 receptors found on the Pilsner cells in the Laphroaig region of the liver. The HEPATIC compound works by inhibiting the active site of the hangoverase enzyme, which produces throb-clusters which enter the blood and attach to the gag-receptors in the brain and the back of the retina (further information on page 212). By inhibiting this enzyme, HEPATIC works by preventing the symptoms of hangover at the source.

More information about the trial

This phase 2 trial will take three years and involve 18 visits to your local trial centre. The centres are in Gunbalanya (West Arnhem Shire), Alice Springs and King Island, Tasmania. Each visit will require 2 pints of blood, a presentation of a week's worth of stool samples and 8 pints of urine (presented in a vessel of your choice). This research is being paid for by the Brewers Research Institute (BRI). The Brewers Research Institute is a company owned by the 'Teenage Alcopop Production Company'.

Pay

You will be paid after attending all 18 visits to your local trial centre. Please note that you can leave the trial at any point you like but you will not be paid and will be asked to contribute toward the cost of the drinks you have consumed.



*Please note that the word 'party' in this document refers to a controlled alcohol intake session, where participants will be given 4 units intravenously every 2 hours for a 48 hour period in isolation. Participants will be actively observed over the full 48 hour period.

Resource 19: Summary of key points on involvement from '*National Clinical Trials Governance Framework and User Guide* (2022)'

The content below is summarised from the National Clinical Trials Governance Framework Component 5, published by the Australian Commission on Safety and Quality in Health Care

Key Requirement for Researchers and Institutions	Direct Quote
Establish systems to support partnership in planning, design, measurement and evaluation	"Systems are designed and used to support patients, carers, families and consumers to be partners in planning, design, measurement and evaluation of clinical trial services." — p. 70
Involved in governance	"involved in the governance of clinical trials within the health service organisation" — p. 89
Involve the public in shared decision-making about participation	"Are involved in planning and sharing decisions about participation in clinical trials." — p. 89
Provide accessible information and support health literacy (including different formats and interpreters)	"involved in the development and review of health information for consumers about clinical trials" "Have opportunity to ask for more information about clinical trials information, in different formats or a translator, if required." — p. 89
Enable people to nominate who should be involved in decisions	"Let the clinical trial workforce know who should be involved in sharing decisions about their participation in a clinical trial." — p. 89
Collect and respond to feedback about trial participation	"Provide feedback to the health service organisation or clinician about experiences of trial participation." — p. 89
Involve public in developing and reviewing public-facing trial information	"Consider being involved in the development and review of health information for consumers about clinical trials." — p. 89

Adapted from this document:
https://www.safetyandquality.gov.au/sites/default/files/2022-05/final_design_-_national_clinical_trials_governance_framework_and_user_guide_-_30_may_2022.pdf

Resource 20: Summary of National Safety and Quality Health Service Standards - Second edition – 2021

Main Point	Direct Quote
Purpose of the Standard	*"Leaders of a health service organisation develop, implement and maintain systems to partner with consumers." (p74)*
Goal of Partnering	*"To create an organisation in which there are mutually valuable outcomes by having consumers as partners… and patients as partners in their own care, to the extent that they choose." (p74)*
Systems for Consumer Engagement	*"Systems are designed and used to support patients, carers, families and consumers to be partners in healthcare planning, design, measurement and evaluation." (p74)*
Partnering in Patient Care	*"Systems that are based on partnering with patients in their own care are used to support the delivery of care." (p74)*
Nature of Patient Partnership	*"Patients are partners in their own care to the extent that they choose." (p74)*
Health Literacy Role	*"Health service organisations communicate with patients in a way that supports effective partnerships." (p75)*
Governance & Design Participation	*"Consumers are partners in the design and governance of the organisation." (p75)*
Definition of Effective Partnership	*"Effective partnerships exist when people are treated with dignity and respect, information is shared with them, and participation and collaboration… are encouraged and supported." (p75)*
Partnership at Individual Level	*"Partnerships relate to the interaction between clinicians and patients when care is provided." (p75)*
Partnership at Service Level	*"Partnerships relate to the participation of patients, carers, families and consumers in the overall design of the service, department or program." (p75)*
Partnership at Organisational Level	*"Partnerships relate to the involvement of consumers in overall governance, policy and planning." (p75)*
Benefits of Partnerships	*"Delivering care that is based on partnerships provides many benefits for patients, consumers, clinicians, health service organisations and the health system." (p75)*

Adapted the National Safety and Quality Health Service Standards - Second edition – 2021 published by the Australian Commission on Safety and Quality in Health: Carehttps://www.safetyandquality.gov.au/sites/default/files/2021-05/national_safety_and_quality_health_service_nsqhs_standards_second_edition_-_updated_may_2021.pdf

Resource 21: Values from Draft Statement on Consumer and Community Involvement in Health and Medical Research

Values

Our values are **respect, partnership, mutual benefit, equity, inclusion, diversity, transparency, accountability, integrity, and safety.**

Reproduced from:
https://consultations.nhmrc.gov.au/research-partnerships/review-of-draft-consumer-statement/supporting_documents/Draft%20Statement%20on%20Consumer%20and%20Community%20Involvement%20in%20Health%20and%20Medical%20Research.pdf

Resource 21: Roles and responsibilities from Draft Statement on Consumer and Community Involvement in Health and Medical Research

Roles and responsibilities of consumers, communities, and consumer organisations

Consumers, communities, and consumer organisations can be **involved in all levels, stages, and types** of health and medical research. Ideally, their involvement will start at the planning stage and continue throughout the research cycle. In addition to their shared roles and responsibilities, consumers, communities, and consumer organisations are responsible for:

- Bringing a **lived experience perspective** to help prioritise, influence, and shape research.
- Using their **community knowledge and connections** to bring a wider community perspective to the research, and to **communicate the research outcomes** to those who will be impacted by it.
- Individual consumers and community members can be involved in **peer review** of applications for grant funding.

Roles and responsibilities of researchers

Researchers **plan, conduct, and disseminate research** in partnership with consumers and communities. In addition to their shared roles and responsibilities, researchers are responsible for:

- Ensuring **consumers and communities are involved** in their research, in line with the values and principles of effective consumer and community involvement.
- Planning for consumer and community involvement before research commences, including allocating budget and time for effective involvement, capacity building, and support.
- Treating consumers and communities as **valued members of the research team.** This can include acknowledging their contributions in publications, involving them in disseminating research outcomes, and offering remuneration for their contributions. Researchers should work with consumers and communities to determine what role they will play and ensure everyone understands their role.
- **Maintaining ethics and integrity,** including complying with ethical standards and regulations, and protecting the rights, privacy, and safety of consumers and communities.

Roles and responsibilities of research institutions

Research institutions **support consumer and community involvement.** In addition to their shared roles and responsibilities, research institutions are responsible for:

- Facilitating consumer and community involvement through clear **policies and procedures**, including guidance on recruitment, remuneration, and complaint handling.
- **Creating a safe environment** by assisting researchers to accommodate the needs of individual consumers and community members.
- Promoting an **institutional culture** where consumer and community involvement is celebrated and expected in research.

Reproduced from:
https://consultations.nhmrc.gov.au/research-partnerships/review-of-draft-consumer-statement/supporting_documents/Draft%20Statement%20on%20Consumer%20and%20Community%20Involvement%20in%20Health%20and%20Medical%20Research.pdf

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